When a Parent has Cancer: An Examination of Providers' Training and Parents' Preparation for Disclosure Conversations

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Dedication

To the courageous souls who have lost their battles to cancer, like my Dad.

&

To the courageous warriors who have survived cancer, like my Mom.

Abstract

Patients diagnosed with cancer who have school-aged children are faced with many challenges, both physical and emotional. These parents seek out guidance from their providers about how to navigate such challenges (e.g., how to tell their children about the diagnosis). However, their requests are often met with hesitation. Currently, there are few studies that investigate how providers can assist such parents with their communication efforts. This paper is comprised of two studies: The quantitative study focused on providers' training and perceptions about their roles related to assisting parents with communication regarding cancer with their children. The qualitative study centered on parents' experiences with having gone through this process – with or without professionals' involvement.

In the quantitative study, the author developed and utilized a survey informed by previous scholarship. Fifty-six (56) providers participated. After running descriptive statistics to learn about the samples' characteristics, two linear regressions were employed to predict the relationship between the number of years providers have practiced and the training they have undergone about how to engage parents and their children in conversations about cancer; no significant predictions were identified. The author then employed a t-test to compare the means of medical providers' and mental health providers' respective perceptions about various roles they presume (or not) vis-à-vis parents. Significant differences were found. A chi-square analysis then illustrated that mental health providers maintain a more open perception towards functioning in sundry roles as compared to medical providers.

In the qualitative study, the author focused on parents who were diagnosed with cancer (n=10) and had the experience of deciding when and how much to tell their school-aged children about it. A semi-structured interview guided by the Circumplex Model of Marital and Family Systems was employed to collect data. Using a thematic analysis method, the author (and two additional coders) then examined interview transcripts. Ten principal themes emerged. Said themes focused on (a) preparation processes that parents go through to learn how, when, and how much information to give children; (b) how to continue cancer-related communication over time; and (c) desires for more direct assistance and information from providers or care navigators in health teams.

Global implications are provided for both studies based on evidence that parents diagnosed with cancer need guidance from providers about how to navigate disclosure conversations with their children. While providers are interested in receiving more training, they do not always perceive it as their role to assist parents. Curricula in education could be revised to include more (and more sophisticated) content regarding provider/patient/family communication. Pedagogical goals should focus on increasing incoming professionals' comfort with interacting with patients and their families (versus only patients) before they get into the field. Training on-the-job can then be facilitated through ongoing coaching (e.g., required continuing education, instructional forums and workshops, or guild conferences). With increased education, knowledge, and experience, providers will be able to better attend to patients' and their family members' needs. In return, parents will be better equipped with support and resources, which will lead to more thoughtful, purposeful, and sensitive conversations with their children.

Table of Contents

List of Tables

List of Figures

List of Appendixes

Introduction

Existing scholarship has focused on how cancer affects the patient, the couple, and, at times, the family system. However, research on communication between parents with cancer and their school-aged children, specifically the disclosure conversation, has not yet been well-attended to. Parents have previously identified providers, such as their oncologists, nurses, and mental health providers, to be the professionals who should assist them during these challenging times (Back et al., 2005; Turner et al., 2007a; Turner et al., 2007b). However, providers have described feeling inadequately trained and poorly equipped to provide such assistance (Ernst et al., 2013; Inhestern et al., 2016). Extant literature illustrates that training providers to work with the entire family system, rather than just the patient, can improve patient-provider relationships. It can also increase confidence levels of providers in working with families (Epstein et al., 2016; Zaider et al., 2016).

Children of parents who have life-threatening diseases are often aware that something is wrong, even without having been explicitly told about the illness (Forrest et al., 2006). However, when children are not informed about the illness, they oftentimes create their own assumptions about what they are witnessing – which can be worse than the reality (Christ et al., 2006; Stein et al., 2019). Therefore, it is vital for both providers and parents to understand ways that children can be told about their parents' illness. Relatedly, it is important to know how much information should be given.

In this original mixed-methods dissertation, the author created and utilized a self-administered measure (Study 1) to gain information from providers, both biomedical and mental health, to ascertain the level(s) of training related to these foci. In addition, their

perceptions about feeling equipped and being knowledgeable to work with the entire family system were assessed. The author constructed and used a semi-structured interview in Study 2 with parents who were diagnosed with cancer and told their school-aged children about the diagnosis. Processes and experiences regarding preparation(s) and who supported parents were investigated. Continued and ongoing communication efforts were also explored. Finally, the participants were asked to describe their needs for more information coming directly from their provider or a care navigator.

Guiding Research Questions

The following questions were informed by the literature outlined above, with Family Systems Theory (Study 1) and the Circumplex Model of Marital and Family Systems (Study 2) as guides.

Study 1:

1. Where do providers receive training to work with parents who are diagnosed with cancer?
2. How much training do providers receive in supporting parents during diagnosis disclosure conversations with their children?
    a) Do years of practice predict training received?
3. How equipped and knowledgeable do providers feel to assist parents with decision-making about disclosure conversations with children?
4. What are the perceptions of roles regarding helping parents discuss their diagnosis with their children?
    a) Do role perceptions differ by provide type?

Study 2:

1. What decision-making processes do parents with cancer go through to disclose their diagnosis to their children?
2. What changes occur within the family system?
    a) How does communication change over time?
    b) How does flexibility change over time?
    c) How does cohesion change over time?
3. Who do parents think can help them disclose - and communicate about - the cancer with their children during their cancer journey?

Together, these two inquiries shed light on the amount of the training providers receive to work with cancer patients and their families. They illustrate the needs of parents when they are going through the processes of deciding when, how, and how much to tell their school-aged children about the diagnosis. Finally, both studies identify key personnel who may be helpful during these times. They are a call for action to train biomedical providers systemically, so that the entire family system is considered in patient care.

Article 1

Providers Working with Parents who are Diagnosed with Cancer: Training and Role Perceptions regarding Communication Efforts between Parents and Children

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Dissertation Article 1

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Synopsis

Introduction: About 20% of adults diagnosed with cancer are parents of children under the age of 18 years. Parents diagnosed with cancer often seek assistance from their providers when it comes to deciding how to tell their children about the diagnosis. However, extant literature illustrates that providers are not adequately prepared to engage with or support patients and their family members in this process(es).
Method: A survey constructed for this inquiry was used to collect data. Descriptive statistics were employed to characterize participants' training background, level of interest to receive more training, feelings of being equipped and knowledgeable to assist parents, care team roles, and provider role perceptions. Two linear regressions were used to analyze the relationship between provider type and receiving specific training. An independent t-test was utilized to compare means between two types of providers (i.e., biomedical and mental health) and their respective perceptions of roles. Chi-square analyses illustrated the differences of perceptions of specific roles.
Results: Findings illustrate that providers primarily receive training about how to work with patients and families on-the-job. Similar results were found related to training specifically on how to support communication efforts between parents and children during cancer diagnosis conversations. However, providers are interested in receiving more training on these matters. Mental health providers were more receptive toward helping parents gather information about cancer (and then facilitating conversations about it with children) than as compared to biomedical providers.
Discussion: Medical and graduate school curricula should include principles of the Patient-Centered Medical Home to create a standard of practice that includes family members in patient care. Continued training during residency and internship to educate providers about all professionals working in integrated teams is indicated. Knowledge about the roles that various providers play could also increase reliable resource provision and effective interdisciplinary collaboration.

Keywords: communication, care team roles, parents with cancer, provider training, providers' role perceptions

Providers Working with Parents who are Diagnosed with Cancer: Training and Role Perceptions regarding Communication Efforts between Parents and Children

Cancer – including breast cancer, lung cancer, pancreatic cancer, and others – represents the second leading cause of death in the United States. In 2020, an estimated 1.8 million new cases were diagnosed in this country, and about 600,000 people died from the disease (American Cancer Society, 2021; Siegel et al., 2020). An estimated one-third of newly diagnosed patients are parents of children under the age of 18 years (Syse et al., 2012).

Many parents who are diagnosed with cancer turn to their providers for guidance during the process of deciding how, when, and how much to tell their children about the diagnosis. Turner et al. (2007a) found that patients wanted information from their providers regarding how to talk to children, but were oftentimes met with passive recommendations to social workers or given the titles of books that they could read on their own. Further, they found that parents thought that the on-staff nurses were in the best position to provide one-on-one information and support, but that said nurses neglected to do so. In fact, when nurses are experiencing a difficult situation, they were more likely to provide generic information that was not requested by parents in hope of controlling the encounter or preventing the parents from engaging in emotional conversations (Turner et al., 2008).

One of the reasons for the lack of help-availability (or utility) for parents with cancer is that biomedical- and behavioral- health providers are often not well-equipped to navigate these decisions and communicative processes. Providers tend to lack training about engaging children in cancer conversations. Health professionals often avoid

conversations with patients about their children due to concerns that doing so will heighten parental stress (Turner et al., 2008). Nurses feel they lack knowledge about the emotional impact(s) or what age-appropriate information to provide (Turner et al., 2007b). When biomedical providers do receive communication skills training, foci generally target "medical interviewing" to complete a physical- or family- history thoroughly – rather than talking to patients and their families about the emotional sides of their illness-related concerns (Back et al., 2005).

Other barriers, too, have been identified as reasons for providers' less proactive efforts in engaging sick parents in conversations with their children. Lack of skills to work with distressed parents can result in providers avoiding the less objective facets of patient's health-related data and care sequences. Structural barriers, like the absence of space on a patient's chart to note special situations (such as having children) and practice characteristics that discourage working with more than one patient-at-time (e.g., HIPAA rules; high patient-visit quotas) further exacerbate providers' neglect of parents' more systemic needs (American Association for Marriage & Family Therapy [AAMFT] et al., 2018; Denker et al., 2017; Mendenhall & Alshareef, in-press).

Literature illustrates, however, benefits for both providers and patients of communication training for medical staff (Mendenhall et al., 2018). For example, Epstein et al. (2017) found that training for oncologists lead to statistically significant improvements in patient-physician relationships. Zaider and colleagues (2016) provided a training module to oncology nurses that resulted in increased confidence in working with families and managing stress. Oncology providers can increase senses of hope in parents

and feelings of inclusion in children by engaging in interactive and open conversations (Turner et al., 2008).

Current Study

This study focused on gleaning insight into how biomedical and mental health professionals' education, preparation, and knowledge serve to support cancer patients who are parents of school-aged children (6-18 years-old, living in the same household). The study was advanced through two main aims: (a) investigate the professional training of biomedical and mental health providers in working with patients and their families in general and communicating with parents who have been diagnosed with cancer and their school-aged children, and (b) determine providers' perceptions of roles toward aiding ill parents in disclosing their cancer diagnosis to said children. For the purpose of this study, working with patients and their families in general is defined by providers including family members during patients' treatment. Such inclusion refers to having family members present during consultations (versus staying in the waiting room) and conversations about the diagnosis and treatment.

The following exploratory research questions guided this effort:

1. Where do providers receive training to work with parents who are diagnosed with cancer?
2. How much training do providers receive in supporting parents during diagnosis disclosure conversations with their children?
    a) Do years of practice predict training received?
3. How equipped and knowledgeable do providers feel to assist parents with decision-making about disclosure conversations with children?

4. What are the perceptions of roles regarding helping parents discuss their diagnosis with their children?
    a) Do role perceptions differ by provide type?

Theoretical Guidance

Family Systems Theory (FST) defines a family as a group of interrelated individuals who work together to function or attain goals (Friednman et al., 2003; Whitechurch & Constantine, 1993). The theory aids in understanding positive and negative adaptations that families make during traumatic and stressful events (Yi, 2009). How families respond to illness may be influenced by various dimensions of family functioning (Rolland, 1994). For example, during cancer treatment, families may experience boundary ambiguities regarding who is inside versus outside of their interpersonal system (Kelly & Ganong, 2011). They may encounter triangulation between members and other types of communication breakdowns (Tolley, 1994). Further, FST views the family as part of a hierarchy of subsystems and suprasystems (Bronfenbrenner, 1979; Minuchin, 1974). Healthcare systems and palliative care units have been identified as suprasystems to which a family possibly belongs (Mehta et al., 2009). Biomedical providers are thereby well-positioned to assist with identifying support systems and otherwise help with communication efforts during a cancer diagnosis (Milberg et al., 2014). Providers who work with cancer patients should focus on the entire family system, e.g., reciprocal influences between multiple members as they collectively cope and adapt to the diagnosis.

Methods

This exploratory study was designed to gather information about the training that providers receive to support cancer-stricken parents in their communication efforts with their school-aged children. It also surveyed providers' perceptions about care team roles and their roles related to assisting parents. Finally, levels of interest to receive more training to work with families and to communicate with families was investigated.

Measure

A survey was created to inquire about providers' training and perceptions of roles to engage with cancer patients and their children. The measure, informed by previous research (e.g., Banerjee et al., 2015; Cherny, 2011; Kim & Salyers, 2008; Zaider et al., 2016), targeted demographic characteristics of providers, the extent of their training, and the role perceptions that they maintain regarding care team roles and their willingness to assist parents in decision-making processes about when, how, and how much to tell school-aged children about the illness. The final measure consisted of 20 main questions with 18 sub-questions (see Appendix A for survey protocol). Queries were written in a manner whereby providers could opt out of any item if it did not apply. The survey was administered in *Qualtrics* (2021), a software platform that allows participants to access surveys easily through a variety of electronic devices (e.g., smartphones, computers, laptops, tablets).

Years of Practice and Location of Providers

Two questions were posed to inquire about the participants' years of practice. Participants were able to fill in the number of years of practicing in their field, as well as the number of years that they have been practicing in their current position. Additionally,

providers were asked to indicate their main setting of practice. Options included: *academic health center, community hospital, comprehensive cancer center, private oncology practice, teaching hospital,* and *other.* For those who selected *other*, a space was provided to write in an answer.

Providers' Training

Eight questions were created to investigate the amount and type of training that the providers received. Questions were broken down into two categories: training in working with patients and their families in general, and training in helping parents during their cancer communication efforts (disclosure and ongoing conversations) with their school-aged children. To better understand where these two types of trainings were received, the questions "Where did you receive training to work with patients' families?" and "Where did you receive training in helping parents during their cancer communication efforts (disclosure and ongoing conversations) with their school-aged children?" were posed. Answer options for both questions were: *in school*, *during residency or post-doctoral training*, *at professional conferences (e.g., workshops, poster sessions, presentations, etc.)*, *during my practice (on the job training, supervisor/mentee meetings, collaboration with peers, etc.)*, and *I have not received any training in helping parents*, or *other.*

Participants who selected the option of *in school* were prompted to answer the following question: "During my training (e.g., graduate school, medical school) I:" with answer options: *took several semesters of classes*, *learned how to work together with a patient and their family*, *took one semester-long class*, *learned how to work together with a patient and their family*, *took classes in which the topic of learning how to work*

together with a patient and their family was covered a few times, *had a few hours of training, learning how to work together with a patient and their family*.

Level of Interest for Further Training

Two questions were posed to inquire about participants' level of interest in receiving more training to work with patients and their families in general and their interest level in receiving more training to work with parents during their communication efforts (disclosure and ongoing conversations) with their school-aged children. A five-point Likert scale from 1 (*not interested at all*) to 5 (*extremely interested*) was utilized.

Feeling Equipped and Knowledgeable to Assist Parents

Six questions focused on providers' feeling equipped for and knowledgeable in assisting parents who have cancer in their communication efforts (disclosing the diagnosis and continuing to talk about the cancer) with their children. A five-point Likert scale from 1 (*strongly disagree*) to 5 (*strongly agree*) was utilized for this subscale; the overall reliability for the scale was good ($\alpha = .75$). Questions included "I feel equipped to talk with parents about how they should tell their children about the diagnosis.", "I feel knowledgeable about in-person resources related to cancer disclosure communication efforts (e.g., support groups, therapists) that are available to parents diagnosed with cancer.", and "I feel knowledgeable about hardcopy and/or online resources related to ongoing communication efforts (e.g., informational pamphlets, books) that are available to parents diagnosed with cancer."

Care Team Roles

Six questions were created to inquire about the participants' beliefs regarding the interdisciplinary care teams helping parents who have been diagnosed with cancer. An

"interdisciplinary care team" was defined as including anyone who is involved in patients' care, such as medical doctors, nurses, mental health providers, or hospital staff (e.g., chaplains, child life specialists, medical technicians). A five-point Likert scale from 1 (*strongly disagree*) to 5 (*strongly agree*) was utilized for this subscale; overall reliability for the scale was good (α= .76). Questions included "I believe it is important for the care team to help parents decide how to tell their children about the cancer diagnosis.", "I believe it is important for the care team to help parents continue to talk about the cancer, prognosis, and treatment with their children", and "I believe it is important for the care team to connect parents to in-person resources about having ongoing conversations about the cancer (e.g., support groups, therapists)."

Providers' Perceptions about their Roles

Six questions were created to inquire about participants' beliefs regarding their role(s) in interdisciplinary teams and how involved they are with helping parents who have been diagnosed with cancer – specifically, in terms of communicating (disclosure and ongoing conversations) with their school-aged children. The questions described different roles and inquired about whether the participants thought said roles were part of their job. The reliability for this subscale was excellent (*α*= .91).

Role perception 1 asked "I believe that it is part of my role to help parents decide how to tell their children about the cancer diagnosis." Role perception 2 asked "I believe it is part of my role to help parents continue to talk about the cancer, prognosis, and treatment with their children." Role perception 3 asked "I believe it is part of my role to connect parents to in-person resources about how to tell their children about the cancer diagnosis (e.g., support groups, therapists)." Role perception 4 asked "I believe it is part

of my role to connect parents to in-person resources about having ongoing conversations about the cancer with their children (e.g., support groups, therapists)." Role perception 5 asked "I believe it is part of my role to provide informational resources to parents diagnosed with cancer regarding disclosure conversations with their children (e.g., pamphlets, websites, books)." Finally, role perception 6 asked "I believe it is part of my role to provide informational resources to parents diagnosed with cancer regarding ongoing communication about the cancer with their children (e.g., pamphlets, websites, books)."

Questions were answered in a *yes* or *no* manner. If the participant selected *no*, a follow-up question was posed to explain why the participant believed the described role was not part of their job description. Options included: *it would be beyond my scope of practice and/or skillset*; *it would be unethical for me to do so*; *I would not feel comfortable*; or *other*. If *other* was selected, participants had the option to write in their answers.

Procedure

Once a final version of the survey was created, it was sent to five providers in the community for their perusal, to test for face validity. This process confirmed that the participants understood the questions in the same way(s) that the author did. Edits were made according to feedback and then sent out to a different group of experts in the field (n=4) for another review. Further edits were made and the survey was finalized.

After receiving approval from the University of Minnesota's Institutional Review Board (IRB), the link to the survey, preceded by a consent form, was sent electronically to the following associations: American Association for Marriage and Family Therapy

(AAMFT), AAMFT's Family Therapists in Healthcare TIN (Topical Interest Network), Collaborative Family Healthcare Association (CFHA), and the University of Minnesota's MHealth system (see Appendix B for recruitment script). Interested participants were able to read the consent form to learn more about the study. Inclusion criteria included being a provider who works with cancer patients (as at least part of their job). Providers who did not interact with cancer patients were excluded from analyses. If the participant consented to take part, they were then directed to the Qualtrics survey. The survey took between 5-10 minutes to complete. Once data collection was complete, said data were exported into SPSS (version 25). The file was protected by using Duo-security and stored in the UMN Box digital location to maintain confidentiality.

Sample

Participants self-identified as 68% female (*n*=38), 30% male (*n*=17), and 2% (*n*=1) preferred not to answer. Eighty-two percent (*n*=46) identified as White, 7% (*n*=4), 4% as Asian (*n*=2), 2% as Asian and White (*n*=1), 2% as Hispanic, Latino, or Spanish (*n*=1), 4% as White and Other (*n*=2), 4% as Other (*n*=2), and 5% preferred to not answer (*n*=3). (Totals do not equal to 100% due to ability to select multiple responses.) The sample included the following professional backgrounds: 68% (*n*=38) Medical Doctors, 13% (*n*=7) Marriage and Family Therapists, 11% (*n*=6) Psychologists, 4% (n=2) Physician Assistants, 2% (*n*=1) Social Worker, 2% (*n*=1) dual Marriage and Family Therapist and Child Life Specialist, 2% (*n*=1) dual Registered Nurse and Marriage and Family Therapist, and 2% (*n*=1) dual Medical Doctor and Administrator. (Totals do not equal to 100% due to ability to select multiple responses.)

Thirty-three (59%) providers worked with cancer patients less than 25% of the time, 10 (18%) providers worked with cancer patients 26-50% of the time, three (5%) providers worked with cancer patients 51-75 % of the time, three (5%) providers worked with cancer patients more than 75% of the time, and seven (13%) worked with cancer patients 100% of the time.

Data Analysis

Descriptive statistics for all variables were computed. Required assumptions of linear regression were tested prior to running the analysis. Linear regressions were used to examine the dependent variables of (a) receiving training in general to work with patients and their families and (b) receiving training in helping parents communicate with their children regarding the diagnosis, and the independent variable of years of practice of providers.

Crosstabs were created to summarize the relationship between the dependent variable of role perception and the independent variable of practice type. This also assisted in illustrating the proportions of cases in each subgroup. The six role perception questions were computed into a continuous score so that each provider had a total score (highest possible score was 6, which indicates that participants believed it was part of their responsibility to engage in the described role). Finally, providers were arranged into two groups: biomedical providers and mental health providers. An independent t-test was conducted to compare the means between the two independent variable groups and the continuous dependent variable of role perception. A chi-square was utilized to illustrate the differences between each role perception (dependent variable) and provider type (independent variable).

Missing Data

Sixty-nine (69) participants were recorded as having participated in the survey; 56 completed it entirely (and were thereby included in this study). Data were removed for the following reasons: six did not meet the inclusion requirements (i.e., being a provider who works with cancer patients (as at least part of their job); one participant did not formally consent; and six did not complete the survey beyond the demographics section. Missing data for the 56-participant sample were managed using listwise deletion (and were minimal). A total of seven participants had missing data. Listwise deletion is a technique often used with smaller samples in behavioral science research (McNeish, 2017).

Results

Years of Practice and Location of Providers

On average, providers have been practicing for 16 years (*SD* = 13.02), ranging from zero to 54 years. The majority (*n*=29, 45%) practiced at Academic Health Centers, while 14% (*n*=9) practiced at Comprehensive Cancer Centers, 19% (n=12) practiced at other locations (e.g., Private Practice Integrative Mental Health Site, Crisis Services, and Non-profit organization), 12% (*n*=18) practiced at Primary Clinics, 9% (*n*=6) practiced at Community Hospitals, and 2% (*n*=1) practiced at a Private Hospital.

Providers' Training

Participants were asked about the amount of training they received to work with patients and their family members in general, as well as helping cancer patients in their efforts to communicate their diagnosis to their school-aged children.

Training to Work with Patients and their Families

Providers received training to work with patients and their family members in various settings. The most common setting (*n*=46, 32%) was on-the-job training (e.g., while practicing, collaboration between peers, and supervisor/mentee meetings). Twenty-seven percent (*n*=38) of providers received training as part of their curricula in medical-, nursing-, or graduate- school. Twenty-six percent (*n*=37) cited residency or post-doctoral training as the place where training was received, and 16 (11%) listed professional conferences. One provider listed "other" as their training location. Four percent (*n*=5) did not receive any training to work with patients and their family members.

Within the providers who received training during school, 38% (*n*=19) listed having a few hours of training, 28% (*n*=14) took classes in which the topic was covered a few times, 20% (*n*=10) took several semesters of classes, and 2% (*n*=1) took one semester-long class on the topic. When inquired about the number of workshops attended, 20% (*n*=10) listed more than five workshops, 14% (*n*=7) listed between three to five, 40% (*n*=20) listed between one to two, and 28% (*n*=14) listed none.

Training to Help Parents during their Communication Efforts

Training sites to helping parents during their communication efforts occurred in numerous settings. Only one participant (2% of sample) received training in during school to aid parents in their cancer communication efforts with children. Five (9%) listed having received this during residency or post-doctoral training, 4% (*n*=2) at professional conferences, and 15% (*n*=8) in on-the-job training (e.g., while practicing, collaboration between peers, and supervisor/mentee meetings). The majority of providers – 64% (*n*=34) – reported not receiving any training, while 6% (*n*=3) reported "other"

(e.g., training from a chaplain). Those who received training (*n*=19) listed that they learned how to aid parents during disclosure conversations (*n*=2), how to hold ongoing conversations (*n*=3), how to do both of these (*n*=11), and how to facilitate general family communication (*n*=3).

Relationship between Years of Practice and Training Received

To answer the question about whether length of practice predicts the training received, two simple linear regressions were calculated to (a) predict receiving training to work with patients and their families based on years of practice, and (b) receiving training to help parents communicate with their school-aged children based on years of practice. This analysis was conducted to inquire about the evolvement and changes in school curricula. The results showed that providers' years of practice did not significantly predict either type of training. The years of practice did not significantly predict training to work with patients and their families in general ($F(1,53) = 1.091$, $p = .301$), with an R^2 of .020. Years of practice also did not significantly predict training specifically to help parents communicate with their children regarding their diagnosis ($F(1(53) = 1.91$, $p = .664$), with an R^2 of .004.

Level of Interest for Further Training

Seven participants (14%) were extremely interested in receiving more training to work with patients and families in general. Twenty-four (46%) were very interested, and six (12%) maintained that they were unsure. Ten participants (19%) stated they were slightly interested in training, and five participants (9%) were not at all interested in receiving further training.

[insert Figure 1 about here]

Eleven providers (21%) were extremely interested in receiving further training specifically to help parents during their communication efforts with children. Fifteen providers (29%) listed being very interested in receiving further training, and six (11%) were unsure. Fifteen providers (29%) were slightly interested in receiving further training, and five (10%) were not interested at all.

[insert Figure 2 about here]

Feeling Equipped and Knowledgeable to Assist Parents

Two questions were asked regarding how equipped the providers felt to assist parents who have cancer in their communication efforts with their children. On average, providers did not feel very equipped to talk to parents about how they should tell their children about the diagnosis ($M = 2.73$; $SD = 1.27$). Similarly, they did not feel equipped to talk to parents about having ongoing conversations within families ($M = 2.86$; $SD = 1.27$).

Four questions focused on the knowledge of providers in assisting parents who have cancer in their communication efforts with children. On average, providers felt less knowledgeable about in-person resources (e.g., support groups, therapists) related to cancer disclosure communication efforts ($M = 2.84$; $SD = 1.18$) than in-person resources related to ongoing communication after the initial disclosure conversation ($M = 3.02$; $SD = 1.24$). In relation to hardcopy and/or online resources pertaining to cancer disclosure communication efforts (e.g., informational pamphlets, books) that are available to parents, providers did not feel knowledgeable ($M = 2.67$; $SD = 1.13$). Similar results were found about hardcopy and/or online resources about ongoing communication efforts ($M = 2.71$; $SD = 1.16$).

[insert Table 1 about here]

Care Team Roles

When asked about the importance of the care team to help parents decide how to tell their children about a cancer diagnosis, the average answer was 4.37 (*SD* = 0.77), meaning providers agreed that this was a role of someone on the care team. Similarly, providers believed it was important for someone on the care team to help parents continue to talk about the cancer, prognosis, and treatment with their children (*M* = 4.31; *SD* = 0.79).

Connecting parents to resources about disclosure conversations was also rated as being an important role of the care team (*M* = 4.45; *SD* = 0.61), alongside connecting parents to resources about ongoing conversations (*M* = 4.37; *SD* = 0.69). Providers believed it was important for someone on the care team to provide informational resources to parents about disclosure conversations (*M* = 4.37; *SD* = 0.63). In addition, providing resources about continued communication was equally important to providers (*M* = 4.37; *SD* = 0.63).

[insert Table 2 about here]

Providers' Perceptions about their Roles

Providers mostly agreed that it was part of their role to help parents, diagnosed with cancer, talk with their children about it. This section of the questionnaire had seven participants with missing data, which were handled using Listwise deletion. Out of the 49 providers, 37 (75%) agreed that it was part of their role to help parents decide (a) how to tell their children about the cancer diagnosis, and (b) 40 providers (82%) thought it was also their role to help parents continue to talk about the cancer, prognosis, and treatment

with their children. Forty-one providers (84%) agreed that it was part of their job to provide information about in-person resources, such as support groups and therapists, to parents who are seeking guidance on how to tell their children about their diagnosis. Forty-three providers (88%) said it was part of their role to provide such resources to help learn about ongoing conversations between parents and children.

In relation to distributing resources, such as pamphlets, websites, and books, 38 providers (78%) thought it was their role to provide these to parents who need help with disclosure conversations. Thirty-seven providers (75%) thought it was part of their role to distribute such resources about ongoing communications regarding cancer to parents.

[insert Table 3 about here]

In cases where providers did not think the described role was part of their job, the most cited reason was that the role is outside of their scope-of-practice (*n*=26, 56%). In one case, the provider listed being uncomfortable engaging in the described role. Finally, seven medical doctors listed "other" as the reason for the described role not being part of their jobs. Those who selected this reason provided written reasons; examples included time constraints and believing that mental health providers are the ones who should engage in such roles.

[insert Table 4 about here]

Relationship between Perceptions of Roles and Provider Type

An independent-samples t-test was conducted to compare means of role perception regarding various roles of biomedical and mental health providers (marriage and family therapists, psychologists, and social workers). One participant was removed

from this sub-sample due to identification of as a dual professional (marriage and family therapist and nurse).

There was a significant difference in role perception between biomedical providers ($M = 4.24$, $SD = 2.18$) and mental health providers ($M = 6$, $SD = 0$; $t(46) = -2.72$, $p < .001$). All mental health providers (n=13) believed that the described roles were part of their responsibility. Biomedical provides (n=35) only selected some of the described roles as part of their responsibility.

A Chi-square test was utilized to illustrate the differences in specific role perception between biomedical and mental health providers. The Chi-square included the two groups – biomedical providers and mental health providers – and each role description (n=6). Results showed that the following were significant: role perception 1 (*I believe that it is part of my role to help parents decide how to tell their children about the cancer diagnosis*) ($X^2(1) = 5.94$, $p < .05$) , role perception 2 (*I believe that it is part of my role to help parents continue to talk about the cancer, prognosis, and treatment with their children*) ($X^2(1) = 4.11$, $p < .05$) , role perception 5 (*I believe that it is part of my role to provide informational resources to parents diagnosed with cancer regarding disclosure conversations with their children (e.g., pamphlets, websites, books)* ($X^2(1) = 3.56$, $p < .05$), and role perception 6 (*I believe that it is part of my role to provide informational resources to parents diagnosed with cancer regarding ongoing communication about the cancer with their children (e.g., pamphlets, websites, books*) ($X^2(1) = 5.94$, $p < .05$). For all significant role perceptions, more mental health providers said it was part of their responsibility to engage in the described roles than as compared to biomedical providers.

[insert Table about 5 here]

Discussion

Findings from this exploratory study highlight the training that providers who work with parents diagnosed with cancer receive, alongside the perceptions of roles related to the assistance of parents with continued communication efforts and provision of resources. Results show a paucity of such training during medical-, nursing-, and/or graduate- school programs.

Previous research has highlighted that patients who are diagnosed with cancer and have school-aged children turn to providers for guidance about how and when they should hold disclosure conversations (Halseth & Ulfsaet, 2003). This study showed that providers did not feel equipped or knowledgeable to assist parents in deciding how to disclose their diagnosis to their children, or about resources that could be suggested to parents. However, providers are interested in receiving further training in working with patients and their families, as well as how they can be of assistance during communication efforts between parent and child.

Education Implications

Findings of this study show that providers do believe that it is important for someone on the care team to engage in roles that assist parents with communication efforts. However, open-ended answers illustrated that biomedical providers are short on time to engage in such roles. Further, they see such roles as the responsibility of mental health providers. This is troublesome, though, because patients seek assistance from their biomedical providers. Such providers' have the capacity and should have the knowledge

to either help or refer patients out to appropriate resources. These findings are grounds for additional training and changes to existing preparatory curricula.

Adding training modules to graduate, medical, and nursing school curricula has been advocated for by others, as well. However, it is unrealistic to continue adding more to already crowded curricula, keeping students in school even longer, or to engage in sundry turf battles about which new foci to prioritize beyond baseline domain knowledge (Mendenhall & Alshareef, in-press). Integrating courses, allowing space for professionals from various backgrounds to work together and learn from one another, is one way of increasing knowledge about both biological and psychosocial implications of being diagnosed with a life-threatening disease (Cuff et al., 2004; Feldman & Feldman, 2013; Sacchi et al., 2021).

Integrating courses with mental health and medical students so that they can learn together, and from one another, may also be a good start. For example, during medical school students often take an introductory course to the profession. This course is a good place to familiarize students with how to engage with the family members of their patient, instead of only with the patient alone. It is important to get the student comfortable to have family members engaged in care. Creating standard practices to include family members (with the permission of the patient) in care discussions, rather than leaving family members in waiting rooms, is vital. This introductory course could also teach incoming medical providers about integrated care (i.e., collaborating with various professionals). The information could include education about the roles of other professions, including mental health providers. Further, it could teach students about the "warm handoff" of a patient and their family members to others on the care team. The

goal is to ensure that the patient and their family members are introduced appropriately to the next provider and given information about how they will benefit from meeting with the new provider.

Training Implications

Lack of training has been cited as a principal reason why providers hesitate to engage patients and their family members in discussions about cancer (Back et al., 2005; Turner er al., 2007b). This study found similar results, with the most common training setting being on-the-job training. Said findings illustrate the need to include training during residency, internship, or fellowship to providers so that they get hands-on experience in working with patients and family members simultaneously.

Compared to biomedical providers, mental health providers appeared to be more receptive towards helping parents with cancer during their communication efforts. This discrepancy could be explained by the schooling and normal day-to-day professional duties that mental health providers engage in. Mental health graduate-school curricula typically include courses and topics that focus on interpersonal communication, making providers more comfortable to engage in conversations about family dynamics (generally) and cancer and death (specifically).

Similar to Turner et al. (2007a), results of this study showed that biomedical providers are willing to provide tangible resources such pamphlets, books, and websites to parents, but do not see it as their role to connect parents with in-person resources like support groups or therapists. This suggests the importance of biomedical providers having better knowledge about available referral resources for parents. Support groups have been identified as valuable for both the ill parent, their partner, and children.

Counseling programs have been developed and shown to enhance well-being of parents and children (Diareme et al., 2007; Lewis, 2011). Such programs have also been found to significantly improve family communication about the cancer (Romer et al., 2007).

While prevalence rates of psychological distress are high among cancer patients, the delivery of mental health services by oncologists is minimal (Granek et al., 2018). Developing screening tools and treatment protocols that oncologist staff can utilize may be beneficial (Muriel et al., 2009; Passik et al., 2002). Such protocols could further assist physicians in identifying their patients' needs for mental health care and make appropriate referrals.

Practice Implications

Reforms in the Patient-Centered Medical Home (PCMH) have called for the advancement of principles to improve the experience of patients and providers alike across a variety of care settings (AAFP, 2007; ACP, 2010; Crabtree et al., 2011; Jackson et al., 2013). Said principles should inform standard-practice in oncology departments. These include physicians having an ongoing relationship with patients as their primary contact within an interdisciplinary, integrated, continuous, and comprehensive care team (AAMFT et al., 2018; Kellerman & Kirk, 2007). PCMH could also assist in an approach to care that is holistic and include family members to be part of the treatment journey. Inclusion of family could benefit the patient by increasing feelings of support. Providers who view patients from a systemic view – considering all aspects what makes the person whole – can lead to establishing better rapport which can result in treatment and medication compliance, leading to an overall better health outcome.

Applying and practicing by the principles of the PCMH could be helpful in addressing issues highlighted in this study, such as biomedical providers not perceiving certain job descriptions - especially ones that are within their abilities and potentially helpful to patients - as part of their roles. All providers working with cancer patients – across primary-, secondary, and tertiary- care settings – could be helpful in assisting parents with their communication efforts and in the provision of concomitantly supportive and available resources.

Limitations

There are several limitations to note in this study. The survey administered was created by the author based on previous research. While the pilot ensured face validity (e.g., by engaging nine experts in its initial version and revisions), the measure still lacks established content validity. Content validity ensures that the measure observes all the constructs that the researcher is interested in testing. Using a newly created measure, rather than an established one, is also problematic in terms of reliability. Reliability is important because it describes the extent to which a measure can be repeated and yield similar results across multiple uses (Drost, 2011). To establish test-retest reliability, for example, similar results utilizing the same measure across studies must be found.

In addition to reliability and validity issues, the study had a small sample size with little variance. This poses an issue for generalizability and reduces confidence in the findings. The sample was made up of mostly medical doctors, with no variance in biomedical provider type (e.g., Medical Doctor, Doctor of Osteopathic Medicine, Nurses). This sample makes it hard to generalize results to different types of providers working with cancer patients. Missing data were handled via listwise deletion, which

compromised the sample size and the effect size even further. Using listwise deletion with a small sample size such as this further increases Type-II error rates. Type II error occurs when the null hypothesis is accepted, but is actually false. Making this type of error can thereby result in a false negative conclusion. For example, the results state that years of training do not predict the extent of training received, when they actually might.

Lastly, all mental health providers answered "yes" to all descriptions of various roles. Cognitive bias could have occurred in an attempt to decrease stigma or increase others' positive perceptions about mental health. Across primary-, secondary-, and tertiary- care environments, mental health providers are still fighting for their place in integrated healthcare teams vis-à-vis biomedical providers (Hodgson et al., 2014; McDaniel et al., 2014; Mendenhall et al., 2018). By stating that they are willing to engage in the various roles described, mental health providers may be attempting to illustrate the importance of their profession. Finally, all mental health provider participants in this sample already had experience in working with cancer patients in some capacity (it was part of the inclusion criteria). Therefore, results cannot be generalized to all mental health providers, such as those who do not work with cancer patients (but might in the future).

Conclusion

About 20% of all patients who are diagnosed with cancer are parents to school-aged children. Such parents are reaching out for help from their providers in decision-making processes about how, when, and how much to tell their children. However, many providers (both biomedical and mental health) are not sufficiently trained to do this, nor do medical providers consistently believe that it is their job to engage in such efforts. This study shed light on providers' lack of training, specifically in regard to helping

parents during disclosure conversations efforts. Overall, findings highlight the need for integrating such training into medical and mental health classroom curricula, in on-the-job training sequences, and through post-graduate care practices. Attention to these pursuits will lead to more responsive and comprehensive care sequences as the standard (not the exception) for cancer patients with school-aged children.

Article 2

When a Parent has Cancer:

Preparing to Disclose the Diagnosis to School-Aged Children

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Dissertation Article 2

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Synopsis

Introduction: Parents who are diagnosed with cancer are faced with difficult decisions related to how, when, and how much to tell their children. Most literature supporting such parents focuses on communication processes after the cancer is disclosed. Knowledge about processes that parents go through to prepare for disclosure conversations with their children is scarce.

Method: Semi-structured interviews were conducted with 10 participants who were diagnosed with breast cancer. Questions were guided by the Circumplex Model of Marital and Family Systems. Transcripts were analyzed using a thematic analysis method.

Results: Ten principal themes were identified from interview transcripts. Parents described how they prepared for the disclosure conversation, ways that cancer was discussed, and how communication evolved as treatment progressed. Results highlight the emotions that parents feel while navigating communication efforts. Specific needs that parents maintain to have healthy conversations with their children were identified.

Discussion: Parents who are diagnosed with cancer would like more support from their providers in how to communicate with their children about their cancer diagnosis. Biomedical providers, mental health providers, and/or care navigators could all engage in such roles – attentively and empathically – as individuals or in collaboration with each other. Improving practices in such manners would be especially helpful in patients' efforts to learn about disease-specific information and courses, navigate the health care system, and make informed decisions about available resources and referrals.

Keywords: cancer, communication, parent and child communication, parents with cancer

When a Parent has Cancer:

Preparing to Disclose the Diagnosis to School-Aged Children

Approximately 40% of American adults will be diagnosed with cancer at some point during their lifetime (National Cancer Institute, 2019). Of these, it is estimated that 18% are parents of minor children (Syse et al., 2012; Weaver et al., 2010). A life-threatening disease, such as cancer, can have an impact on the physical, emotional, and social well-being of each member of the family (Dalton et al., 2019; Osborn, 2007). Parents who are diagnosed with cancer are faced with juggling many challenges, including accepting and adapting to the diagnosis while still fulfilling parental roles.

Coming to terms with one's own cancer diagnosis is challenging. Having to tell school-aged children (6-18 years old) about the diagnosis can be one of the hardest conversations a parent has to have. Deciding how to disclose it to – and how to continue talking about it with – one's child can be very difficult. Parents are unsure about how much their children will understand, do not know what age-appropriate information to give them, and are not clear about how to support and facilitate effective means of coping. They want to protect their children from the changes that a cancer diagnosis brings, such as uncomfortable shifting of roles within the family (Ares et al., 2014; Finch & Gibson, 2009). Parents also wonder whether the ill parent, the healthy parent (if present), or both parents should take part in the conversations (MacPherson, 2005; Smith et al., 2019). The initial disclosure conversation can set the tone of how the cancer will be continued to be talked about. The disclosure conversation differs from other hard conversations the parent may have had because of the imminent reality or the possibility of death.

Literature Review

Several studies have highlighted the importance of informing children about their parents' life-threatening conditions. Although unable to comprehend the severity of the illness, younger children (3-6 years old) are often aware of the changes in physical appearance and capabilities of the ill parent (e.g., losing weight and hair, fatigue, loss of appetite) that come with such diagnoses (Beale et al., 2004). Children as young as six years old understand that cancer can be life-threatening, and even suspect that something is wrong before being informed about it (Forrest et al., 2006). Zhao et al. (2015) found that 80% of children who were not told about their parents' life-changing diagnosis knew about the illness from their own observations or from other people. Keeping the diagnosis a secret can leave children to make their own assumptions about what they see and experience, which can be worse than the reality (Christ et al., 2006; Stein et al., 2019). For example, children who are not specifically told about their parents' disease often blame themselves or worry that they have caused the illness (Christ et al., 2006; Kennedy & Lloyd-Williams, 2009). Offering accurate information and thorough explanations can provide reassurances and comfort that the child is not at fault, nor at risk for contracting the same illness (Forrest et al., 2009; Kristjanson et al., 2004).

Researchers have not yet agreed on age-appropriate information that children should receive. Children (4-19 years old) who had partial information (i.e., knew their parent was sick but did not have extensive knowledge about the illness) about their parents' life-altering diagnosis were found to have more social and emotional difficulties compared to those who had no information at all or received total disclosure about the condition (Nelson & While, 2002). Child age was found to have a significant effect on

how much information was given and if the word “cancer” was mentioned by the parents (Barnes et al., 2002). Adolescents tend to understand more and recognize the potential significance of their parents’ illness compared to younger children (Giesbers et al., 2010). This understanding influences the adolescents’ developmental tasks of separation and individuation (Stein et al., 2019), leading parents to be more cautious with the information that they share (Kennedy & Lloyd-Williams, 2009; Nam et al., 2009). However, children often want information from various sources, such as their parents, healthcare providers, and other resources, like books or the internet. The extent of information that children need varies with different stages of the disease(s), as well. Children tend to want more information at early stages of diagnosis compared to later stages, with desired information focusing on helping parents (rather than information about the disease itself; Kennedy & Lloyd-Williams, 2009).

Research has focused on the relationship between communication about a parents’ illness and children’s psychological health. Positive family relationships, in which members are encouraged to share their feelings, were associated with lower anxiety and depressive symptoms in adolescents (12-19 years old) whose parents had cancer (Harris & Zakowski, 2003). Similarly, children (6-16 years old) who were explicitly told by their parents about the diagnosis and the severity of it, were found to have lower levels of anxiety compared to those who were not told (Kennedy & Lloyd-Williams, 2009; Rosenheim & Reicher, 1985). Finally, a positive correlation between the perception of the severity of cancer and stress levels of children has been found (Huizinga et al., 2005a). Associations between communication processes and post-traumatic stress disorder (PTSD) have also been explored. Problematic communication (e.g., absence of

sharing feelings, avoiding talking about the illness, inability to pose questions) was associated with greater symptoms of PTSD in children (11-18 years old) whose parents were diagnosed with cancer (Huizinga et al., 2005b).

Due to feelings of discomfort in parents, conversations about cancer with children often focus on the diagnosis itself, thereby avoiding communication regarding the prognosis, treatment course, or possibility of death (Lewis et al., 2006; Shands et al., 2000). Talking about these details is difficult for parents because they want to avoid overwhelming the children. Thus, parents diagnosed with a life-threatening disease often want support regarding what to say to their children, especially from healthcare professionals (Halseth & Ulfsaet, 2003). Families coping with caner have been identified as a vulnerable population who needs special attention from healthcare professional (Tafjord, 2021). However, knowledge about the availability of support, actually accessing such support, and the quality of said support varies greatly among parents (Ernst et al., 2013; Inhestern et al., 2016).

Current Study

The aim of the study presented was two-fold: (a) identify the decision-making processes that parents with cancer go through to disclose their diagnosis to their school-aged children; and (b) explore parents' views about who can help them disclose and communicate about their cancer with their children throughout the cancer journey.

Theoretical Guidance

This study was guided by the Circumplex Model of Marital and Family Systems, which provides a lens to explore the family as a unit in its interactions within the context of a larger environmental system (Olson, 2000). The three fundamental dimensions of the

model are cohesion, flexibility, and communication. The model considers the respective levels and balance of a family's cohesion and flexibility (with communication as a facilitating dimension of these two continua). Family cohesion measures the emotional bonding between family members across four levels (disengaged, separated, connected, and enmeshed). Family flexibility measures how systems balance stability versus change across four levels (rigid, structured, flexible, and chaotic). Communication measures the family's skills in listening, speaking, self-disclosure, clarity, continuity and tracking, and respect and regard.

Methods

Ten participants were interviewed. Inclusion criteria comprised: (a) parents who have had cancer, (b) children were between the ages of six and 18 years old during the parental illness, and (c) some type of conversation occurred between the parent and the child(ren) about the cancer.

Procedures

After receiving approval from the University of Minnesota's Institutional Review Board (IRB), data collection commenced. All participants were recruited via a snowball method (see Appendix C for recruitment script). Participants were asked to share the study description with other possibly interested participants. New participants contacted the author via email and set up a time to conduct the interview. Nine interviews were conducted via telephone; one was conducted in a private office. Each participant was provided with a consent form via email a few days prior to the interview so as to offer ample time to review, sign, and return to the researcher (see Appendix D for consent form). Before the start of each interview, the author reviewed the consent form again,

provided time for questions, and asked for additional verbal consent to proceed with the study.

Measure

A semi-structured interview was conducted by the author to ensure consistency, while allowing flexibility to obtain important information through follow-up questions. Interviews consisted of 28 questions which were grouped into four parts: (a) demographic questions (*n*= 7), (b) diagnosis background (*n*=3), (c) communication with children (*n*=7, with 10 sub-questions), and (d) conclusion (*n*=1). The author paused during the third section to ensure again that participants continued to consent and agree to the interview. The interview process lasted between 35-55 minutes. Open-ended questions in the third section were the main emphasis of the study; focusing on the experience of participants in making decisions about how to tell their children about the parents' diagnosis of cancer. Participants were asked to recall how they prepared themselves to disclose their diagnosis to their children, and how much information was given during the first conversation. Participants were asked about their ability to answer their children's question about the diagnosis and what type(s) of questions they were unable to address. Questions regarding continued communications and what they looked like were posed. Parents were asked to identify any providers that were helpful in facilitating the conversations, and to distinguish between those were helpful versus those who were not (see Appendix E for interview protocol).

All interviews were audio-recorded and transcribed verbatim. The author removed all identifying information (e.g., names, places, religious affiliations) to protect confidentiality. All recordings and transcribed documents were stored in a safe digital

location, safeguarded by Duo-security. Only the author and the authors' advisor (Tai Mendenhall, Ph.D., LMFT) had access to raw data.

Data Analysis

Transcribed data were coded and analyzed following a thematic analysis method as outlined by Crabtree and Miller (1999). Through an iterative, reflexive, and reductive process, phrases and words were identified and sorted into categories, themes, and subthemes. Six stages in the analysis were followed: (a) transcripts were perused, recording emerging topics; (b) each transcript was assessed independently for a second time and summarized; (c) a list of identified topics was created and clustered by similarity and abbreviated into codes; (d) transcripts were examined once more and codes were applied, while observing for more potential topics to emerge (e) to reduce the number of codes, the most descriptive codes were identified and grouped into categories, based on similarity and relatedness; and (f) major themes within categories were separated out by subthemes and integrated into an comprehensive picture. These stages were repeated with each transcript until saturation was reached.

Coding began after the first interview was transcribed using an Excel spreadsheet (*Version 16.43)*. The author also engaged in memoing, noting anything that stood out, seemed especially important, or memorable. After the author and her advisor coded the first transcript, individually and reviewed together, a list of codes was created to check for similarities and to create preliminary categories and themes. After the initial code book was created, both the author and her advisor went back to the first interview to apply the codes and edit as necessary (see Appendix F for codebook). Several meetings were held to create a first draft of the codebook (see Appendix G for audit trail). The

author then applied the codes to each of the remaining nine interviews. After each interview, the codebook was updated, revised, and edited as necessary or indicated. Regular meetings were held between the author and her advisor to review, discuss, and revise the codebook.

A third researcher was also included in the coding processes. The authors' advisor and this additional researcher coded randomly selected interviews to ensure consistency and confirm non-biased analysis of the transcripts. After all interviews were coded, meetings with the authors' advisor and the additional researcher were held (separately) to review respectively coded transcripts and ensure consensus of coding. All discrepancies in coding were discussed until they were resolved. Discrepancies between coders rarely occurred.

To ensure trustworthiness, the research process and data analysis were documented and disclosed, the author's self-of-the-researcher was discussed, and the author's biases noted (see Appendix H for reflexive memos). Lastly, the authors' advisor and the third researcher were included in the analysis and interpretation to reduce misrepresentation of the data and reach consensus. The author and her advisor met regularly to discuss coding processes, emerging categories and themes, and collective interpretations of the transcripts. The third researcher and author also met several times to discuss interpretations and code applications to the transcripts.

Sample

All participants (N=10) were female and diagnosed with breast cancer. Their ages ranged from 42 to 72 years old (M =54.7; SD=8.8). Age at the time of diagnosis ranged from 31 to 52 years (M=44.3 years; SD=6.1). Eight participants were married, one was

single, and one was divorced. Participants self-identified their race as the following: one Asian, one Black, one White and Hispanic, and seven White, non-Hispanic. Educational levels ranged from some college (*n*=2) to bachelor's degree (*n*=3) and graduate degree (*n*=5). One participant had three children, seven participants had two children, and two participants had one child. Children's average age at the time of their parent's diagnosis was 14 years old (*SD*=5.03). Participants reported on a total of 19 children (14 females and 5 males).

Results

The following are common themes and categories found to be imperative to parents when they were disclosing and communicating about the cancer diagnosis to their school-aged children. Results illustrate how parents prepared for the disclosure conversation, how it was conducted, who was helpful, and who they believe was or could have been supportive. Codes represented changes in family functioning, the participant honoring the self, lack of social support from friends and extended family, and emotions that emerged during the cancer journey. Further, commonalities among language and memory issues, as well as the salience of the medical environment, were found. Finally, insights about how providers could have been more helpful were provided. While some illustrative quotes are integrated throughout this section, see Table 6 for a more comprehensive listing. While the codebook was utilized to guide the result headings, multiple codes were merged into one for the purposes of flow.

Preparing for the Disclosure Conversation

Three categories emerged regarding preparing to have the disclosure conversation. Parents gauged the right timing for such conversations by awaiting official

results and waiting for a time that would not be disruptive to the child's routine. Many parents also engaged in their own research by looking for information online, reading various resources, or talking to family members and professionals. The actual conversation about the diagnosis with children usually occurred in a way that provided opportunities for the child to process information and ask questions. Participants talked about being straightforward and honest, especially when they felt optimistic about their diagnosis and prognosis.

Ambiguity

Participants recalled a certain sense of ambiguity – waiting to find out what type of cancer they had, waiting for appointments, and general uncertainty about what will happen once they were diagnosed. Such ambiguity was hard on both the ill parent and the children because often the children could sense that something was wrong, but the parent wanted to wait until they had all the information before talking to their children about it.

Parents described that during such times of ambiguity they had a hard time being present and often found their minds wandering and speculating about worst possible scenarios. Most notably, participants recalled that in order to find out about their diagnosis, they had to go through numerous tests over a long period of time and with obstacles (including difficulty scheduling, insurance challenges, and having to wait a long time between receiving tests and results).

Gathering Information before the Conversation

Participants sought out information to prepare for the disclosure conversation. Some parents pursued in-person resources by going to talk to professionals (e.g., doctors, mental health providers, religious leaders). Some parents talked to others who have had

similar experiences (e.g., friends who have coped with cancer). Others obtained informational resources on the internet or bought books to educate themselves about how other parents handled this situation. Participant 005 recalled, for example: “I wanted to research better how to approach the topic. So, I read articles and I searched online for resources to find out how others have done it.” Often, parents talked about leaning on their own knowledge and experiences in handling hard situations, such as telling their children that a grandparent had died or having the sex talk. Recalling how previous hard conversations were handled, and how the children reacted, helped parents gauge how to hold a disclosure conversation about cancer. Participants recalled leaning on their husbands for support in collecting such information, as well.

Timing of the Conversation

As mentioned above, all parents had their complete diagnosis and prognosis before sitting down with their children to have the disclosure conversation. Parents also waited until the news of the cancer would not disturb important and ongoing sequences in their children’s life. Participants talked about aligning the disclosure conversation, for example, with school schedules. Many parents waited until summer vacation or other planned breaks, such as spring or winter break, to talk about their diagnosis. Parents emphasized that it was important to them not to distract their children from their studies.

Having the Disclosure Conversation

After deciding on the right time to have the disclosure conversation and preparing themselves for it, parents shared their experiences of actually holding the talk. Providing a safe physical space (e.g., quiet environment, private room) to talk about the diagnosis and allowing children to ask questions seemed vital during the disclosure conversation.

During the conversation, parents described focusing on relaying a positive message, explaining what cancer is, and talking about what it meant. Parents also described using age-appropriate language with their children.

Participants placed an emphasis on the medical facts of cancer rather than their own emotions, ensuring that their children had a chance to create their own feelings around it. Further, the mothers were attentive to the reactions of their children and acted accordingly; examples included providing emotional support (e.g., physical touch, assuring that the parents will be fine) or giving more information if needed. In some cases, parents were also ensuring that the child knew that the cancer was not caused by something that the child did or said, so as to reduce feelings of guilt or fear. Participant 008 remembered:

> I told him that he didn't do anything wrong. Kids that age can think that they got in trouble or something like that. So that was kind [of] something we made sure to tell him, 'no you didn't do anything wrong'.

Involvement of Children

Once the children were informed of their parents' cancer, they tended to become physically and emotionally supportive (e.g., attempting to be helpful whenever possible). Some parents allowed their children to be involved in their treatment process, such as visiting at the hospital, attending meetings with the care team, and taking part in educational classes the parent participated in.

Treatment Process

Parents were willing to include their children in the treatment process (e.g., allowing them to accompany them to treatments, meetings with the doctors, and attend

educational classes with the parent). According to the participants, such involvement was beneficial for both them and their child(ren). Having the children present during consultations with medical providers, for example, ensured that the child understood what was going on with the parent. Consultations provided opportunities for the child to ask questions, if needed.

Participants emphasized that whenever there were educational classes, children were happy to be a part of these and took advantage of the opportunity to learn more about the cancer. The children often benefited from such experiences because they were provided information that otherwise would not have been gained. Further, attendance prevented the children from receiving incorrect information, like they could if they did an internet search by themselves. Participant 003 explained: "She asked lot of questions when we were there with the lady about food and appetite and about diet and what she could do to help."

All parents recalled the importance of children being present and meeting with providers. Described benefits to the child and the parent related to opportunities to learn more about the specific cancer, sundry treatment options, and what side effects of medications could occur. Having this knowledge prepared both the children and the ill parent for the upcoming changes with the appearance of the mother (e.g., weight loss, hair loss).

Supportive Children

In most cases, the children of the ill parent were supportive in ways that – according to participants – decreased the stress of the parent. Children attempted to point out the silver linings of cancer (e.g., the chance to spend more time together, becoming

an overall stronger person – both physically and mentally), be present for the parent during and after treatments, and offer emotional or tangible support. Parents explained that the experience made their children more empathic and sympathetic towards other people going through difficult times in their lives.

It is important to note, however, that sometimes it appeared that the boundary between being supportive of parents versus being parentified were crossed. Parents sometimes described how their children took over responsibilities like caretaking other siblings, managing financial matters, and other duties that are more developmentally recognized as adult or parental in nature (Chen & Panebianco, 2020). Participant 007 explained: "She would call comb her sisters' hair and try and do all that. And she kind of took on managing the finances also. She kind of took over, telling people how to act and what to do."

Children Reaching Out and Doing Research

After becoming informed of their parents' cancer diagnosis, the children often took things in their own hands and conducted some type or research about the diagnosis. Many children went online to get information and understand what the diagnosis meant for their mothers. Others created class projects that focused on cancer as a way to learn more about it. The children also often reached out for help from parents, peers, and – at times – school counselors, in processing the information and gaining more knowledge. Across these sequences, participants described themselves as working to be a resource of information for their children. They provided children with resources for their perusal, most often in form of books or bringing them to talk to a professional.

Family Functioning

In almost every case, participants described their family's functioning shifting in important ways. Families had to adapt to new routines, change their relationships with one another, and modify their communication styles.

Family Flexibility

Though cancer often changes a great deal, parents attempted to keep things as "normal" as possible for their children. They tried to ensure that children's lives would go on undisrupted, such as continuing important school and extra-curricular activities. Parents actively made efforts to spend more time (e.g., family dinners, leisure time) with their children to ensure stability, as explained by Participant 007: "At that time, we had family meetings, just to keep the dynamics in the house and things under control, we [are] all on the same page and just to teach them rules and regulations."

Flexibility, which focuses on changes within leadership, roles, and rules within a family, seemed to be balanced, as described by participants. Leadership roles of parents appeared to be shared across the participants' cancer journey. Roles within the family systems were stable but changed when necessary. The mothers recalled that their husbands took over responsibilities, for example, that would usually be within the participants' duties. Children were flexible in accepting the power structure changes (e.g., fathers giving rides to school or preparing meals when mothers usually did these things). Discussions about such role-changes were conducted in an open manner that included the children.

Family Cohesion

Participants described that the cancer diagnosis brought their family closer due to the sensitivity of the life-threatening disease. Cohesion, which relates to the emotional bonding in family members towards one another, within family members increased. The mothers illustrated that they felt that their husbands and children, alike, became more emotionally available to them – and that the experience, overall, increased their feelings of interpersonal closeness.

Even when participants' children were at developmental stages where they would otherwise be inclined to draw away from parents and become more independent (i.e., during adolescence), children were characterized as spending more time with – and becoming more emotionally close to – the ill parent. For example, Participant 006 remembered: "She [was] worried about her mother and this person that she's supposed to be breaking away from." Parents of adolescents understood the balance that their child needed between spending time together and apart. Those parents made a conscious effort to ensure interactions between them were balanced. Participant 009 said, for example:

> I'm trying to get him to be more independent as a young man. But he's still relying on mommy. Like if I'm here, he still wants me to do certain things for him that when I'm not here, he'll do on his own.

Family Communication

All participants talked about communication sequences with their children. Parents were focused on keeping children informed whenever there were decisions to be made about the treatment or related changes to the overall functioning of the family. Parents emphasized the importance of frequent communication focused on not

overloading the children with information. All parents thought it was important to have ongoing communication about the cancer itself, as well as the treatment they were going to receive – but it was also important to them to gauge how much the child wanted and could handle, based on their age and maturity level, and commence from there.

Open and honest communication. All participants talked about being open and honest with their children and the importance of their children being up to date with their parents' health. Open and honest communication occurred when the parents were willing to share all the information they had with their children, regardless of how frightening or discouraging the conversation may be. It was important for parents to include the children in the highs and lows of their treatment process. Open communication also meant that chances for questions and expressing emotions were provided. This meant that children were allowed to voice their fears, concerns, or any other feelings that they had.

Honoring the Self

Participants expressed how important it was for them to take time to care for themselves in several aspects of their life. Some started making more time for themselves physically, while others worked to ensure care for their mental health. They also relied on spiritual aspects to make it through their cancer journeys.

The women focused on healing their bodies by engaging in self-care activities. Parents recognized that they needed to be healthy in order to be able to take care of others. Participant 005 thought about all the aspects of what makes her a parent and where she needed support: "Your body is getting fixed or healed or whatever. You've got these other aspects that make a complete parent. And how do you think about supporting those in such a time?"

Many of the ill mothers relied on some kind of spiritual guidance during their cancer journey. Some recalled keeping religious faith and some talked about higher powers or knowing there is a reason for their disease. As Participant 004 explained, “If I didn’t die when I had stage four melanoma, God has me here for a particular reason and He’s not done with me yet.” Keeping faith supported participants during the harder times of their trajectories.

Emotions of the Parent

All participants went through a range of emotions throughout their cancer journey. Parents described feelings of positivity, protecting children, fear, and guilt, as well as experiences of agency and communion in the medical environment. These emotions were experienced by participants throughout their cancer journeys.

Positive Outlook

Participants described trying to keep a positive outlook on the entire situation. Having a positive outlook influenced the ways that parents communicated with their children. A positive outlook led mothers to portray an optimistic message to their children. A good prognosis (e.g., having caught the cancer early or having a less aggressive cancer) shaped the participants’ overall outlook on the situation. Participants described that their positive outlook on the cancer created a sense of strength that they could survive the cancer.

Previous experience with cancer. Many participants described how having previous experience with cancer in a family member or a friend affected their outlook on their own diagnosis, usually for the worse and especially if that family member died. Participants

recalled how seeing a family member go through cancer provided some knowledge about the treatment process(es) ahead and prepared them for the possibility of death.

However, when the cancer was survived by their relatives or friends, participants described feeling encouraged. One participant had an extensive family history of cancer, alongside having personally dealt with melanoma during her own young adulthood:

> My whole family has had cancer. I told [my children], 'your grandmother had it. Look at her, there's nothing with her, she is fine'. And then I actually had stage four melanoma when I was like 25. But by the grace of God, it did not hit my lymph nodes. I went in and they removed the mole. (004)

Protecting Children

All parents attempted to protect their children from undue emotional harm, and were thereby careful with the ways that they communicated or relayed information about the cancer throughout their treatment process. Parents recalled that, regardless of children's age, they felt the need to guard them so that the child would not experience excessive anxiety, fear, or guilt. There seemed to be a balance that parents were attempting to reach between protecting the child and giving information without inducing injury. Participant 002 described this in saying: "I think the last thing, as a parent, that you want is your kid to have anxiety and have this horrible fixture. But if they are definitely curious and want information, then you definitely give it to them."

Fear and Guilt

Mothers talked about feeling fear and guilt when it came to the diagnosis and how their children would experience it. Fear occurred when mothers did not know if they would survive their cancer, and that they would leave their children to grow up without a

mother. In addition, they felt fear that the children were not going to be able to process and cope with the news that their parent is diagnosed with a life-threatening illness.

Participants expressed feeling guilt when they spoke about their children and their sacrifices. The parents felt that their children were often worried about losing the parent, taking on extra responsibilities, and missing out on activities that they would otherwise participate in. The cancer placed a hardship on the children, per participants' reports, regardless of how much the parents tried to avoid this.

Agency and Communion

Parents had several opportunities to experience agency and communion during their treatment processes. Agency focuses on the ability to be autonomous and independent within the medical community. It places emphasis on a person being actively involved in their care and being able to make informed personal choices whenever possible. Communion is the concept of being part of a community in which the patient feels supported by their care team as well as their family and friends. It focuses on teamwork while coping with the illness, rather than facing it in isolation (Doherty & Mendenhall, 2019; Tyndall et al., 2014).

Agency occurred, for example, when Participant 007 took charge of her own treatment plan: "I changed treatment programs three times, because each one was so aggressive that after one treatment I couldn't do it, so then I changed my treatment program." Communion was described by Participant 005, for example, when she shared how it is important to think about and recognize the roles of social support: "Create your circles of influence, find this out. And then from the medical professionals, from the

medical community standpoint, maybe creating ‘here is all who are a part of your community or support’.”

Worrying about Extended Family

In a few cases, participants talked about worrying about how their parents would take the news. Thus, they decided not to tell them about the diagnosis or kept information to a minimum. They described how their parents were ill themselves (e.g., Alzheimer’s Disease, Parkinson’s Disease) and would most likely not fully comprehend the severity of their (the participants’) cancer diagnosis. Further, participants did not want to burden themselves with having to constantly remind their parents about the illness, if the parent would forget due to their disease(s) or age-associated cognitive declines. Most of the participants already had a strong will to fight and survive the cancer, so they did not feel like telling their parents and making them worry would benefit anyone. Finally, participants expressed that they did not want to make their parents feel obligated to help them out. They remembered not wanting their parents to go out of their way to assist them with daily chores or child-care very much. Consequently, participants tended to not to share their diagnosis with their parents.

Social Circles

Building upon aforementioned descriptions of communion, participants described having family and friends who supported them, emotionally and physically. The mothers recalled how reaching out to others was essential to them. Participants who had supportive friends experienced a strengthening of emotional bonds. Some participants expressed the lack of support from family and friends.

Emotional Support

Participants explained that having a wide circle of social support was very helpful. They recalled that having emotionally supportive friends, ones whom they could talk to about their fears, frustrations, and hopes, helped with overall perceptions of how well the participant was doing. Having emotionally supportive friends was helpful to the mothers, too, in coping with all the changes experienced by the family system. Finally, participants described how friends who were supportive led to a closer relationship in general. After surviving the cancer, emotionally supportive friends were often described as life-long friends by the participants. Finally, descriptions of emotionally supportive husbands were provided. Emotional support was described as providing reassurance and being compassionate with all members of the family.

Tangible Support

Tangible support was described as helpful behaviors that the participants' friends engaged in, such as helping out with the children (e.g., driving them to school, helping with homework assignments), making meals, taking over chores, and being present during treatment sessions. Participants described friends stepping in where the parent could not and ensuring to keep the children busy. Tangible support was also experienced when participants described how their friends kept them company during chemotherapy treatments. Often, for example, such friends would drive the participant to appointments and stay with them throughout the treatment. Participants understood that their friends have their own busy lives, so they appreciated it a great deal when they took time to help.

Lack of Support

Some participants described having less support than they desired. Participants described how their extended family and friends stopped reaching out as frequently,

compared to the time before they (the participant) got sick. At times, the support ceased because family and friends did not agree with the treatment route the participant had decided on. Lack of support was also experienced by participants when family members compared the participants' cancer diagnosis to their own diagnoses or illnesses (i.e., they turned conversations about the participants' cancer into conversations about their own illness or diagnosis).

Medical Journey

Without being prompted, all parents shared their diagnosis and treatment stories. Said stories included the initial conversation they had with their doctors when their cancer possibility was recognized, the processes they underwent to find out their exact diagnosis, steps taken to ascertain their prognosis, and discussions about possible treatment courses and plans. Treatment stories about chemotherapy, self-healing, and the outcomes of treatment were commonly shared, as well.

Diagnosis and Treatment Story

Diagnosis stories were recalled in detail, including meetings with doctors and the various tests that participants endured. Participants recalled being surprised by how many different providers they had to meet with in a short amount of time. Participants often described having a difficult time focusing on the message being relayed by their provider once the diagnosis was confirmed. Several recalled having to go back with their spouses to hear the specifics again.

Treatment conversations were also remembered as having to decide which route will be taken, as well as cope with any challenges that occurred (e.g., unexpected reactions to treatment or the cancer progressing). Many described how their oncologist

did not give them comprehensive information, specifically when it came to the numerous treatment routes that were available to take. Once treatment did start, the women recalled how they felt, emotionally and physically, and how this affected them and their families. Participants described – at least temporarily – not being able to parent effectively and relying on other family members in-response.

Memory Issues

Some participants had a hard time recalling details pertaining to their treatment or experiences during it. In some cases, too, participants had a difficult time remembering the timeline or particular events that occurred. In other cases, it seemed like the participant had blocked out certain memories altogether, as a way to protect themselves or their children.

When recalling her treatment process, for example, Participant 001 talked about how no one in her family remembered the details: " I don't know why nobody remembers. I asked my husband, I asked my other daughter, I asked my younger daughter and it's like, no one [remembers]." Other participants talked about how the treatment affected their memory and their brain: "The chemo brain makes you forget everything." (002) Similarly, Participant 010 described: "My brain is like Swiss cheese now. I have a hard time remembering things."

Salience of Medical Environment

Participants recollected their experience with the medical environment. Most of the memories they shared were negative ones, in which they did not feel comfortable or did not receive the caring support from their providers, that they desired or needed. The environments of treatment centers were described as depressing (e.g., dark rooms, no

music, crowded with ill people) sans stimulating hope. Parents described that more positive environments are needed, in which rooms are filled with calming stimulants such as music, color on the walls, with welcoming signs and comfortable furniture. Additionally, participants described their medical providers as having been part of their negative experiences, stating that most did not take their time to engage in deep conversations beyond the objective medical facts and issues at hand.

Mental Health Services

Several of the participants had experiences with being referred to mental health services by their medical providers or staff. Some participants shared that referrals came from the insurance companies themselves. The mothers mentioned how at times this was helpful and beneficial, but that other times it felt unwanted.

Some participants did not have a good experience with their assigned mental health providers. Bad experiences included wanting help and not receiving it, connecting with a mental health provider without any follow-up from the provider, and working with unprofessional providers. Others described calling several locations, which were referred by their providers, without receiving a response back.

Post-Treatment Life

All participants talked about some type of adjusting process to a new life post-cancer. This was done via engagement in shifting their mindsets or establishing a new identity without cancer. Many participants found meaning of their cancer from volunteering and participating in research and community groups. Finally, participants also reflected on how cancer changed and did not change their identity.

Adjustments

All participants talked about the changes they had to make after they were officially considered in remission. Changes included their outlook and perspective on life, their diets, and relationships with select people. Many recalled how they began to appreciate things more, especially time. Participants revealed that they attempted to educate themselves as much as possible to try and prevent recurrence and lead an overall healthier life. As Participant 006 remembered: "After I was finished with treatment, I read everything I could about Western medicine and complimentary medicine."

Growing back lost hair was mentioned by all women. Having hair again was seen as a symbol that cancer was behind them. Participant 003 recalled: "And I remember my daughter saying, 'now you don't look like you have cancer'. In my mind, when I finally grew my hair back – that was a healing part." Others talked about taking the time to adjust to a new physical look, and how this was not always easy. Some participants described their feelings about their new body after a mastectomy. Many were surprised by how many various emotions they felt after their physical appearance changed. They recalled, too, making time to grieve their old bodies as they learned how to accept their new ones.

Getting Involved to Cope

Several women got involved in groups, volunteering opportunities, and even with political parties to try to process, heal, and cope. Many spoke about getting involved in groups to raise money, awareness, and increase research regarding disease prevention and treatment methods. The women described that it was (is) important to them to become involved; some cited they did it for their kids, while others wanted to see change in the

ways that cancer care is provided. Many women expressed hope that their involvement will lead to more research to understand the disease better and find a cure.

Identity of Ill Parent

Participants recalled how they worried about the perception of cancer and what others would think. At times, cancer was all they would see and talk about, which made it seem like the disease became part of their identity, even though they did not want it to. Other times, participants made a conscious effort to not let the cancer become part of who they are. Efforts to avoid cancer becoming their identity included reframing the ways that cancer is seen and thought about. As Participant 005 described: "Structuring my understanding and chang[ing] the meaning that I assigned to the whole idea of cancer." Similar to language used when talking to the children about the diagnosis, participants focused on not assigning the cancer any other meaning beyond it being a medical disease that can be treated and cured.

Language Centered around Cancer. Participants recalled how the language around cancer was either an isolating or ostracizing experience. "Cancer", the word alone, was often described as a word that provoked feelings of uncertainty, since it is often associated with death. The language used by their providers induced fear or hopelessness as well. As Participant 007 described: "They have a social worker when I was first [diagnosed], I don't know how they were trained. But anyway, she told me, 'Oh, you have cancer. So, are you dying?'." The mothers described that they made a conscious effort to not use the typical language that is employed when communicating about cancer. They did not want the cancer to become a part of their identity, thus they did not allow language that would do so, be part of their daily communication.

When describing the language used when someone has cancer, the parents compared other life events that occur. For example, Participant 001 compared cancer and a car accident: “I don’t call myself in remission. I don’t call myself cancer free. Am I survivor? Why is cancer being separated? Like, somebody who was in a car crash, they don’t say, ‘I’m a survivor’. It can happen again.” Finally, participants recalled that the language used by their friends was often discouraging and not supportive. Many participants informed that language used by friends, which was viewed as unsupportive, was done intentionally. However, the importance of choosing language that will not hurt or worry anyone was highlighted here.

Need for More Information and Care Navigators

Participants expressed a lack of information and support received from their medical providers and staff. Often, they were told which treatment route to go with and were not given options. They were not provided with information about other available possibilities. Some participants did not receive full information about possible side effects until said effects were happening to them. As described by Participant 007: “They didn’t tell me ‘this will be what your body’s going to go through’. They never told me that when they told me about the treatment. They told me after the fact that I had taken one dose.” In all cases, participants expressed frustration and a want for all possible information to be given, regardless of professional opinion or preference.

Participants described the need for a patient navigator or advocate. Everyone described how it would have been helpful to have someone who is trained to deal with cancer and has extensive knowledge about treatment options, side effects, and other medical complication that may happen. They also expressed wanting someone who could

help with communication efforts. For example, parents thought a navigator could be helpful in assisting parents in deciding how to share the diagnosis with their children, and how the conversation should continue throughout the ensuing treatment process. Further, participants identified the need for an advocate who could normalize their experience and ensure that the medical and mental effects they are experiencing are nothing out of the ordinary.

Discussion

The results of this study describe processes that parents who are diagnosed with cancer go through when preparing to disclose their illness to their school-aged children. Such preparation processes can impact parents' perspectives of their diagnosis, and help them come to terms with the cancer. Further, preparation processes allow the parent to learn about the language and words best used to avoid frightening children and gather information about how to respond to children's' reactions and questions (Krauel et al., 2012).

Results echo other research that says parents place emphasis on the importance of disclosing the diagnosis to their children in a manner that assures correct information is given and assumptions of children are addressed (Christ et al., 2006; Forrest et al., 2006; Kennedy & Lloyd-Williams, 2009; Stein et al., 2019). Communication within the family of origin often increased during the early stages of cancer and continued to be open, honest, and frequent throughout the parents' treatments. The study also highlighted the parents' need for support during the time of preparation for the disclosure conversation, which aligns with the findings of Halseth and Ulfsaet (2003). The findings from this

study give specific examples of how such resources can be sought after and who could be available to parents who seek assistance.

A range of emotions were accentuated by the participants. These represent the complexity of the journey that a parent goes through when diagnosed with cancer. Such emotions need to be recognized by both the ill parent and the family members. Acknowledged emotions lead to processing them better, and thus may be helpful to communicating efforts about the cancer. Feelings of agency and communion spoke to the importance of being involved in one's own treatment. It is important for patients to be able to voice their concerns – and be part of the decision making – about their treatment courses. Providers should allow the patient and their family members to be part of the treatment care team.

An optimistic outlook allowed for open discussions about the cancer diagnosis. This demonstrates that the way the diagnosis is disclosed by the provider and how it is perceived by the patient, will affect the ways that the parent tells their children about the cancer. This finding adds to the importance that providers take their time to talk to their patients, inform them fully, while focusing on medical facts. Providers need to allow for ample time for questions that patients may have and engage in further discussions, as necessary.

Family cohesion, flexibility, and communication were increased during the cancer journey. Parents and children often turned towards one another for support, communicating openly and frequently. The cohesion levels of each family were described as balanced, insofar as family members could lean on one another while also having independence and separateness when needed. Participants described that family members

felt connected to each other, too, while ensuring to give adequate space, both physically and emotionally within these connections. Family members adapted to their new roles and responsibilities without much reluctance. Communication within the family system was highlighted as open, within both (healthy) listening- and speaking- capacities. Collectively these findings align with the tenets of the Circumplex Model of Marital and Family Systems' hypothesis that balanced families function better than unbalanced families (Olson, 2000). And while a cancer diagnosis can disrupt any number of baseline family dynamics, it can also create an opportunity for members to talk more, grow closer, and adapt (through problem-solving, role-negotiation, etc.) together.

Disclosure Conversation Preparations

This study begins to fill a gap in the research by highlighting that parents do in fact go through a preparation phase after they get diagnosed with cancer. Regardless of the diagnosis and prognosis, parents understand the significance of having the disclosure conversation with their child(ren). The initial disclosure conversation can vary vastly from the continued communication that occurs about the cancer. The disclosure conversation can set the tone of how the cancer will communicated about in the future. Thus, it is a very important conversation that needs to in a calm and informative way will help the child process the news better, compared to having a conversation that is conducted in a worried and hyper-vigilant manner.

Parents undergo an intensive preparation process by reaching out for support from personal relationships. Those who have been through a cancer diagnosis were a helpful resource for newly diagnosed parents. They are able to provide resources and guides that were helpful. Professional support was sought after as well. Thus, any provider who has

contact with the patient should be able to help facilitate disclosure conversations, or at the very least refer them to a worthy resource.

Care Navigators

A care navigator (sometimes called a "patient navigator", "patient advocate", or "care coordinator") was identified by parents as especially helpful when medical and mental health staff are not available. Navigators are well-positioned to provide assistance to the patient and their family members about decisions regarding disclosure conversations, continued communication efforts, available resources to explore, etc. (Kashima et al., 2018). They have extensive knowledge about the health care system (and how to navigate it), and can bridge gaps in coordination and communication efforts between multiple providers (Cox et al., 2021). This position can be presumed by a professional or a community health worker who has had personal experience with cancer (Cox et al., 2021; Olaniran et al., 2017). Navigators have been found to improve medication compliance and overall health outcomes in cancer patients (Roland et al., 2017). As they become more integrated into contemporary health care systems, competency-based trainings are being generated in synchrony (Kashima et al., 2018; Pratt-Chapman et al., 2015).

Empathic and Helpful Providers

This study emphasizes that providers, both biomedical and mental health, who work with cancer patients need to be more empathic and helpful during their interactions with cancer patients. With the understanding that providers are limited in available time with each patient, efforts to increase empathy and helpfulness need to be uncomplicated and easy to engage in. For example, integrating more empathic language into interactions

with patients and their families is vital for positive care outcomes. Empathic language includes responding to a patient's concerns in a manner that evokes understanding and compassion, rather than dismissing it with medical jargon (Epstein, 2013).

Ensuring that patients have the support they need is also a good step towards being a more helpful provider. Providing support (or referring out to receive support) should be on the checklist of each provider when engaging with cancer patients. Finally, acknowledging the patient as a person (not just the disease they are treating) is vital. Recognizing that patients are part of a family system, who may require attention as well, could make increase patient satisfaction.

Limitations

There are several limitations to note in this study. First, the recruitment methods relied on a snowball sampling strategy. Further, participants shared the study script with potential participants who had to contact the researcher themselves. The researcher was not allowed to contact possible participants and therefore relied on them contacting her. Relying on participants to contact the researcher can limit contact numbers due to participants hesitancy to reach out. The snowball recruitment method limited the enrollment of new participants to those who were recommended by existing participants. Since all participants were connected in some way, their journeys could have been similar due to utilizing the same providers, health care systems, or referral sources. Likewise, they may have similar stories since many participants were friends who could have supported one another throughout their cancer treatment and journeys.

Second, variance in cancer type and demographic background was scarce. All participants were diagnosed with the same type of cancer (i.e., breast cancer). Having a

sample with a range of cancer types could lead to a better understanding if there are differences in disclosure conversation. It could also affect the way the conversation is held, since breast cancer has one of the highest survival rates, compared to other cancer types (e.g., liver, lung). There was little variance in cultural and ethnic backgrounds. A sample with a more diverse background could allow for better understanding of how cultural and ethnic differences impact the way people talk about life-threatening diseases, such as cancer.

Another limitation relates to the methods in which interviews were conducted. As a result of the COVID-19 pandemic, all but one of the interviews were conducted via telephone. In-person interviews have a benefit of establishing rapport, often times faster than over the phone, and therefore a possibly deeper connection between researcher and the participant. Further, in-person interviews allow for opportunities for the researcher to demonstrate responsiveness to the participants' content via physical cues such as nodding, smiling, or hand gestures. For those reasons, it is possible that in-person interviews may have provided greater detail, shifting the way the results were presented.

Although three researchers were involved in the analyses phase of the interviews, it is possible that interpretations were partial as a result of all three researchers representing the same background of study and field (i.e., family therapy). All three researchers have engaged in the same educational training, too (i.e., Ph.D. in social science discipline) and therefore may have a certain approach to data analysis and reporting results. Including a member outside of our field, in the research team may have shifted the results by having a different interpretation of the transcripts. Finally, while it may not necessarily be considered a limitation, it is important to note that each story told

by the participant was very unique and each had distinctive experiences. The results are a pairing of common themes found from all interviews. However, they are not exclusive and do not encompass individuals' experiences.

Conclusion

When a parent is diagnosed with cancer, it is an emotionally stressful event that can result in extensive changes within the family system. Understanding how parents with school-aged children disclose the diagnosis and continue communicating about it, is vital so that providers, both biomedical and mental health, can offer helpful support and assistance. Parents are willing to do their own research about what to tell their children, but at times need support from providers in finding or accessing resources. Providers must be willing and able to assist parents in their communication efforts. Finally, care navigators are well-positioned to assist parents with their preparation to have disclosure conversations and facilitate ongoing communication. They maintain skills to help parents cope with mental health distress, understand treatment options, and navigate challenges that the family system may face.

Global Implications of the Two Studies

Results of the two studies presented here suggest a lack of provider-training (and a lack of confidence in such training) to support parents who are diagnosed with cancer in their efforts to talk about it with their school-aged children. This is an important pattern to recognize because decisions about when, how, and how much to disclose to children – and how to continue conversations with children over the course of treatment – can be very stressful. Parents are saying that they would like the support, and providers are saying that they are open to receiving more training about how to offer or coordinate such support.

There are several ways to think about responding to these foci. To improve provider and patient communication and increase provider/patient/family interactions, integrating content into course curricula and training sequences could be beneficial. Several models of incorporating such communicative content have been developed and tested, e.g., Setting, Perception, Invitation/information, Knowledge, Empathy, and Summarize/strategize [SPIKES] (Baile et al., 2000; Houseini, 2020), Prepare, Evaluate, Warning, Telling, Emotional response, Regrouping preparation [PEWTER] (Keefe-Cooperman & Brady-Amoon, 2013; Keef-Cooperman et al., 2018). This is important because combining communication- and relationship- building skills within the longstanding and well-established time constraints, heavy course loads, and high patient visit-quotas of medical education and practice can be a tall order (Fiscella et al., 2017; Mauksch et al., 2008). Teaching (and supervising in real-time) efficient and sensitive ways to open visits and begin difficult discussions, gather and share information, gain understanding about patients' and family members' perspectives, reach agreements about

presenting problems or treatment plans, and summarize next-steps within care meetings all represent practices that scholars have found possible in the advancement of care without slowing it down (Keen et al., 2015; Schirmer et al., 2005; Starks et al., 2017; Wittenberg et al., 2018). In fact, purposefully attending to these skills has been linked to higher patient- and family- satisfaction with care, better health outcomes, and reduced medical costs (Buum et al., 2019; Epstein et al., 2005; Mauksch et al., 2008).

Across education and training sequences there is value to purposefully structuring classroom and clinic/hospital learning so that students and trainees gain familiarity with – and skillsets in – practicing in an integrated health care model. Learning and applying principles of the PCMH, for example, can set the stage for providers' capacities to work collaboratively with other professionals. Instead of having any one provider type (e.g., physician) who is perceived as all-knowing by their patients and families, team-care models should to be advanced. Such models provide a broad range of experts working together, compared to one provider doing it-all. Offering opportunities for biomedical and mental health trainees to work concurrently will facilitate skillsets in inter-professional collaboration, care coordination, and service referrals (Hartley et al., 2019). Research has paired training and practice patterns consistent with these methods and foci with similarly positive outcomes as those outlined above for provider and patient communication (Carlson et al., 2012; Chunchu et al., 2012; Granek et al., 2019; Mauksch, Farber, & Greer, 2013).

After foundational training and related preparatory sequences (classroom, internship, residency, fellowship, etc.), all providers are required to undergo continuing education to maintain and/or renew their licenses. Through participation in local,

national, regional, and international conferences, workshops, educational forums, etc., providers must work to stay-current with evolving understandings about (a) baseline care practices and (b) treatment methods/content unique to their specialty. Established practitioners could – in similar ways to early-career professionals described above – take part in trainings to learn about how they can most effectively engage in collaborative teamwork and/or effective communication with patients and their families during care visits (generally) and collaborate within oncology teams and support cancer patients who are parents (specifically). For example, the Accreditation Council for Graduate Medical Education (ACGME), American Society of Clinical Oncology (ASCO), Collaborative Family Healthcare Association (CFHA), Society for Teachers in Family Medicine (STFM), and other guild-specific and cross-guild groups regularly advance annual, semi-annual, and targeted trainings dedicated to improving providers' knowledge, skills, and practices in the advancement of high-quality care (ACGME, 2021; ASCO, 2021; CFHA, 2021; SFTM, 2021).

Future Directions

To better understand how communication begins and then changes over-time in families wherein parents are diagnosed with cancer, future studies should employ longitudinal study designs. Qualitative inquires could include follow-up interviews with both parents and children to observe these processes. Research questions with children could include: How have your parents continued to communicate about the cancer with you? Do you feel like your parents have been open and honest with you about the diagnosis? How comfortable do you feel asking your parents questions regarding the illness? How receptive are your parents to answering your questions about the cancer?

What, if anything, would you change about the way your family communicates (or does not communicate) about the cancer? What advice would you give to other parents who are figuring out how to tell their children about cancer, or having ongoing conversations about it? Research questions with spouses of the ill or deceased parent could include: If you could have the disclosure conversation with your child(ren) again, what would you do differently? What would you keep the same? How has communication about the cancer increased or decreased in your family? How have the ways that you talk about cancer stayed the same or changed? What advice would you give to other parents who are figuring out how to tell their children about cancer, or having ongoing conversations about it? Collectively, studies exploring questions like these could inform knowledge about how communication efforts change over time, and in doing so, better equip providers in their support for all family members (e.g., the ill parent, the spouse/partner, and children).

Quantitative studies could formally measure changes in communication over time, utilizing established tools such as the *Parent Adolescent Communication Scale* (PACS) or *Family Avoidance of Communication about Cancer* (FACC) scale. Moreover, studies should recruit and focus on the spouse of the ill person, in addition to the ill parent. This could point out the processes relevant to communication with children when only one parent is present (versus two). Recruiting spouses could also highlight how communication changes within the couple. Finally, including all members of the family could allow for a holistic view of communication challenges/barriers, strategies, and strengths experienced by the family members. Including multiple research studies on the same foci, utilizing established tools, could lead to more robust collective findings or

similar results, which would increase confidence in the manners that providers then use those results to guide the work that they do. Further sophistication in findings (e.g., regarding individual vs. dyadic vs. parent/child patterns) could assist providers in refining and personalizing that work to better support different subsystems within the whole family during their cancer journey (e.g., how to have disclosure conversations, how to facilitate continued communication, how to support or coordinate support through referrals and resource provision).

To advance knowledge regarding providers' comfort levels and ability to work with – and communicate with – patients and their families, future qualitative inquiries should focus on perceived personal and practice-related barriers and how they can be overcome. Investigative questions could include: What experiences do you have in working with patients and their families? What communication strategies do you employ when working with patients and their families? Are – or were – you hesitant to have patients' family members in the consultation room (and if so, why)? What would make you feel more comfortable to have patients' family members in the consultation room? What benefits do you perceive from having patients' family members in the consultation room? What challenges (practice-related, administrative, financial, etc.) are the most difficult to navigate when working with whole family? How can such challenges be addressed? What wisdom could you share with new medical students or other providers who are beginning their training in this kind of work?

Finally, family communication about cancer likely varies in accord to cancer type. This is because considerable differences exist across respective cancers' prognoses, courses, and survival rates. While the importance of offering straightforward and

objective information might remain constant (no matter what type of cancer is extant), the manners in which parents talk with children about more aggressive cancers (e.g., liver, lung) will likely differ from the ways that they talk about less aggressive cancers (e.g., breast, melanoma). Future research should explore this with greater depth, so as to better-inform patients, families, and providers about ways to traverse these very difficult conversations, alongside what practice patterns in referrals and collaborative care sequences are paired with best outcomes.

Conclusion

This dissertation serves to advance knowledge about how parents who are diagnosed with cancer talk with their children about it, and the manners in which providers can best support them in doing so. Findings illustrate that parents are looking for guidance from their providers, but that providers often do not feel equipped or feel ready to help. Although said findings have limitations, and future research about this topic is highly needed, data gathered serve as grounds to more purposefully advance training in provider/patient/family communication and interdisciplinary team collaboration. Efforts will be consistent with providers' energies and investment in offering the highest quality care, and – more importantly – responsive to patients' needs for purposeful engagement, guidance, and support as they navigate complex decisions about how to talk with their children about cancer.

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Table 1
Providers Feeling Equipped and Knowledge to Assist Parents

	Strongly Disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly Agree (5)
I feel equipped to:					
talk with parents about how they should tell their children about the diagnosis.	20% (*n*=10)	29% (*n*=15)	20% (*n*=10)	21% (*n*=11)	10% (*n*=5)
talk with parents about how they should have ongoing conversations about the diagnosis, prognosis, and treatment.	20% (*n*=10)	21% (*n*=11)	20% (*n*=10)	31% (*n*=16)	8% (*n*=4)
I feel knowledgeable about:					
in-person resources related to cancer disclosure communication efforts (e.g., support groups, therapists, etc.) that are available to parents diagnosed with cancer.	16% (*n*=8)	25% (*n*=13)	24% (*n*=12)	29% (*n*=15)	6% (*n*=3)
in-person resources related to ongoing communication efforts (e.g., support groups, therapists, etc.) that are available to parents diagnosed with cancer.	16% (*n*=8)	22% (*n*=11)	16% (*n*=8)	39% *(n=20)*	7% (*n*=4)
hardcopy and/or online resources related to cancer disclosure communication efforts (e.g., informational pamphlets, books, etc.) that are available to parents diagnosed with cancer.	18% (*n*=9)	27% (*n*=14)	31% *(*n=16)	18% (*n*=9)	6% (*n*=3)
hardcopy and/or online resources related to ongoing communication efforts (e.g., informational pamphlets, books, etc.) that are available to parents diagnosed with cancer.	18% (*n*=9)	27% (*n*=14)	27% (*n*=14)	22% (*n*=11)	6% (*n*=3)

* Cronbach's α= .75, *N*=51

Table 2
Providers' Perception of Care Team Roles

	Strongly Disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly Agree (5)
I believe it is important for the care team to:					
help parents decide how to tell their children **about the cancer diagnosis.**	2% (*n*=1)	0% (*n*=0)	6% (*n*=3)	43% (*n*=21)	49% (*n*=24)
help parents **continue to talk** about the cancer, prognosis, and treatment with their children	2% (*n*=1)	0% (*n*=0)	8% (*n*=4)	45% (*n*=22)	45% (*n*=22)
connect parents to in-person resources about **how to tell** their children about the cancer diagnosis (e.g., support groups, therapists).	0% (*n*=0)	0% (*n*=0)	6% (*n*=3)	43% (*n*=21)	51% (*n*=25)
connect parents to in-person resources about **having ongoing conversations** about the cancer (e.g., support groups, therapists).	0% (*n*=0)	0% (*n*=0)	12% (*n*=6)	39% (*n*=19)	49% (*n*=24)
provide informational resources to parents diagnosed with cancer regarding **disclosure conversations** (e.g., pamphlets, websites, books).	0% (*n*=0)	0% (*n*=0)	8% (*n*=4)	47% (*n*=23)	45% (*n*=22)
provide informational resources to parents diagnosed with cancer regarding **ongoing communication** (e.g., pamphlets, websites, books).	0% (*n*=0)	0% (*n*=0)	8% (*n*=4)	47% (*n*=23)	45% (*n*=22)

*Cronbach's α= .76, *N*=49

Table 3
Providers' Perception of their Roles in Helping Parents

I believe that it is part of my role to: _____	help parents decide how to tell their children about the cancer diagnosis		help parents continue to talk about the cancer, prognosis, and treatment with their children		connect parents to in-person resources about how to tell their children about the cancer diagnosis (e.g., support groups, therapists)		in-person resources about having ongoing conversations about the cancer with their children (e.g., support groups, therapists)		provide informational resources to parents diagnosed with cancer regarding disclosure conversations with their children (e.g., pamphlets, websites, books)		provide informational resources to parents diagnosed with cancer regarding ongoing communication about the cancer with their children (e.g., pamphlets, websites, books)	
Provider Type	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Medical Doctors (*n*=33)	12	21	24	9	25	8	27	6	22	11	21	12
Marriage and Family Therapists (*n*=5)	5	0	5	0	5	0	5	0	5	0	5	0
Social Workers (*n*=1)	1	0	1	0	0	1	1	0	1	0	1	0
Psychologists (*n*=6)	6	0	6	0	6	0	6	0	6	0	6	0
Child Life Specialists (*n*=1)	1	0	1	0	1	0	1	0	1	0	1	0
Nurse & MFT (*n*=1)	1	0	1	0	0	1	1	0	1	0	1	0
Others (*n*=2)	2	0	2	0	0	2	2	0	2	0	2	0

Table 4
Open-ended Answers regarding Providers' Perception of their Roles

Provider Type	Open-ended Answers
Medical Doctor	Though I do take care of cancer patient, I treat the infectious complications of their cancer and I do not feel that it is my role to discuss prognosis or other cancer related issues (Role Perception 1, 2, 3, 4, 5, & 6)
Medical Doctor	Time constrains, I can start the conversation if brought up by a patients but do not have time to initiate this discussion. (Role Perception 1) Too much discussion may stress out a parent even more. (Role Perception 4) Professional Psychologist or SW are great at this (Role Perception 5)
Medical Doctor	Time limitations of a primary care visit. If I had time, then it would certainly be in my scope of practice. (Role Perception 1)
Medical Doctor	I have a patient. I am here to help the patient with his/her medical condition. There are an infinite number of things he/she may not do as I would see fit. If they ask for help or advice, I would be happy to offer my opinion, but I think the idea that there is a "right way" to address these issues is naive. (Role Perception 1) I would have significant disdain for any physician who would presume to know how I should interact with my children. If I were to ask, I would be grateful for their opinion, but I would be equally grateful for my neighbor or postman's opinion. (Role Perception 2) I would be happy to refer them to resources if they are interested, as I am happy to refer them to outside medical resources or other interests they may have. Sharing knowledge is a pleasure, but these are important conversations for which I cannot imagine a playbook that would work in all, or even a majority of settings. (Role Perception 5)
Medical Doctor	Social work and nursing should help with giving these details. (Role Perception 3, 4, 5, & 6)
Medical Doctor	Due to COVID (Role Perception 3 & 4)
Medical Doctor	Social Workers/Palliative care can usually help with this. (Role Perception 5) Primary Care Clinic/Social Workers Domain. (Role Perception 6)

Table 5
Provider Type Differences and Perceptions of their Roles

Variable	Medical Providers (*n*=35)		Mental Health Providers (*n*=13)		Test Statistic for Differences between Samples (N=48)
	M	*SD*	*M*	*SD*	
Role Perception	4.34	2.18	6	0	*t* = -2.720***
	Number (%)		Number (%)		X^2
I believe that it is part of my role to:					
help parents decide how to tell their children about the cancer diagnosis					5.9*
Yes	23 (66%)		13 (100%)		
No	12 (34%)		0		
help parents continue to talk about the cancer, prognosis, and treatment with their children					4.1*
Yes	26 (74%)		13 (100%)		
No	9 (26%)		0		
connect parents to in-person resources about how to tell their children about the cancer diagnosis (e.g., support groups, therapists).					3.6
Yes	27 (77%)		13 (100%)		
No	8 (23%)		0		
to connect parents to in-person resources about having ongoing conversations about the cancer with their children (e.g., support groups, therapists).					2.5
Yes					
No	29 (83%)		13 (100%)		
	6 (17%)		0		
provide informational resources to parents diagnosed with cancer regarding disclosure conversations with their children (e.g., pamphlets, websites, books).					5.3*
Yes	24 (69%)		13 (100%)		

No	11 (31%)	0	
provide informational resources to parents diagnosed with cancer regarding ongoing communication about the cancer with their children (e.g., pamphlets, websites, books).			5.9*
Yes	23 (66%)	13 (100%)	
No	12 (34%)	0	

*$p < .05$, ***$p < .001$

Table 6
Example Quotes of Qualitative Findings (Themes and Categories)

Theme	Category	Example Quotations
Preparing for Disclosure Conversation	Ambiguity	001 – "*The problem with cancer is that it doesn't matter if it's cancer; what matters is what kind of cancer it is. It takes forever to find out. Things happen in a way too slowly and too quickly. Like you adjust to the fact that you have cancer. I have cancer in one breast. The next day, I find out I have cancer in two breast. The next thing is, what kind of cancer? Like you're waiting, waiting, waiting. There are so many different tests that you need to do. Then you're waiting for the staging you and you're waiting for what kind of cancer or how far is this spread."* 002 – *"When the biopsy came back positive probably within that week. Within a week or two, once I had more information as to what the diagnosis and prognosis was. So, I'd have as much information that I could tell my kids."* 009 – "*And then you have to do all the testing, you know? So, one test will take you to another test. And then obviously if you get into the biopsy, that's pretty scary with going through all the testing because they wouldn't continue the testing if they didn't think that you probably had cancer."*
	Gathering Information before the Conversation	001 – "*So what I did was that as soon as I was diagnosed, I reached out to other women that I knew, who went through this. And one of the women had little kids, but she's the one who kind of first told me, 'Oh, be careful how you tell the kids.' And then she sent me a link with some information about, you know, how to talk to the kids."* 008 – "*So, I wanted to go to an expert. I mean, there's tons online, but I just thought I'd rather talk with somebody that dealt with this and that's working with kids that age. And so that was really, really helpful, in terms of like the language that they recommended using. And then I found some really, really great books, resources."* 002 – "*Asking how is it that you delivered important information in the past? Looking back at a previous experiences to what went well, what didn't go well and tailor your message that way. Maybe it wasn't cancer, but something other big, life changing event and how did that child respond? What gave them anxiety? What gave them comfort?"* 003 – *"We talked a lot about it before we told them about it. But the good thing that I had is that I had already talked to my oncologist."* 005 – "*I did also speak with my family, like with my husband."* 008 – *"We had a meeting before we told him the week prior; we met with the school principal and his classroom teacher and the guidance counselor."*
	Time of Conversation	009 – "*At that time, my son had just started his freshman year of high school. And he was always a football player, a basketball player, and stuff. So, it was really hard for me because I thought, 'well, my God, how's this gonna affect my kid?' So, we found out Friday, Friday the 13th. And, um, we told [son] on Sunday."*

		008 – *"And with that timing being pretty close to the end of the school year, we wanted to see if we could get him through the school year without knowing, just so that it wouldn't be a distraction and that he could just have fun and focus on school. So, we didn't tell him until the weekend before his last week of school. We told him like on the Saturday before his final week."*
Having the Disclosure Conversation		001 – '*We picked her up and she was in the car and all I remember is she said, 'Oh Mom, you have cancer; you're gonna die.' And she started like crying in the car and we said, 'no, what makes you think that?' kind of thing. And then, you know, we had the conversation and then we explained to her that she should not look up anything on the internet. If she has questions, she needs to come to us and that we will be telling her the truth because we didn't want her to go to the internet, freak out. Find all this information that might not even apply to you."* 002 – "*You want to give them as much information as they're comfortable, [if] they want to hear more, give them more, but don't download like everything and overwhelm because maybe that's not what they want at the time, you know, so maybe over time if they ask more questions and dig deeper into that. [It was] an ongoing conversation, so especially when I was going through chemo and you know, just having the side effects of chemo, I just kept on reassuring my children that what they were witnessing was not the disease, but the treatment."* 003 – "*The [oncologist] told me there are like 12 different types of breast cancer alone, but he told me he knew what to do with mine and he knew my chance, my survival percentage was really high. So, I kind of had an advantage in telling them that I had an excellent chance of me surviving. So, we talked a lot about what to tell them and we decided to include them completely in the process*." 004 – *"I just said, 'look, I've got breast cancer. I'm going to be fine. I'm just going to have the surgery to have it removed and that's it'."* 005 – *"So, I explained, this is going to happen next and we're going to have the treatment and then I'll be okay. But I pretty much treated it in a very medical manner."* 007 – *"In one of our family meetings, I explained to them what breast cancer was and that I had it and that I would be getting medical attention to take care of it and let them ask questions."* 008 – *"We said that Mommy had cancer and that I would be getting medicine and going to the hospital"*
Involving Children	Involvement in the Treatment Process	001 – "*I did take my oldest one to the doctor many times. So, she got to know the doctors. She got to know my oncologist. She got to know the plastic surgeon. I think it's important that they go; I think it's important that they see the doctors and hear the conversations and then sometimes I think she was asking questions. I think it helps them know the seriousness."* 003 – "*Someone that was talking to them, that have seen other families through it. I think that was huge. Even though the class was just two classes an hour each. It was very thorough, extremely thorough. Everything that they told us that I would be going through, and I would be experiencing how it would be feeling. They didn't hold back at all. And it may have been because of the age of my children, but it was extremely beneficial."* *006 – "My daughter and my husband come to my first treatment so that [daughter] could see what it was like."*

		008 – *"He did come to my last appointment, my oldest son and he couldn't go in for chemotherapy, but we did ring the bell."* 009 – *"My son was a part of everything, he was a part of every step of it."*
	Supportive Children	001 – "*My youngest one who was at home, had to take care of me because with the mastectomy. So, she had to help me bathe, I couldn't really use my arms, so she had to drive me everywhere. She had to open the doors for me."* 003 – "*My son took me to chemo every single week after that [be]cause he got his learner's permit and he drove me to chemo every single Monday, that whole summer. I had to have a double mastectomy and my daughter, she came in for that. Anything that I had that was major, she was there along the way."* 010 – *They were very understanding and passionate and empathetic, and helped out and checked on me. They made me feel better, they empowered me and that was good."*
	Children Reaching Out and Doing Research	004 – *"My oldest did some kind of project in high school and she did it on [cancer]. She's done research and she knows enough of the background."* *008* – "I had two books, one was 'The Summer My Mom was Bald' which was kind of a fun book just about hats and scarves and the way that your mom's looks change. And then another book was written from the perspective of a kid about a little older than he was about having a parent who had cancer, but then like on the sidebars, the science was introduced as well. 'What is cancer? What is a tumor? What's chemotherapy?'" 009 – *"He must have done his own research about it. He came back to me says, 'you know what Mom, 80 or 90 percent of women they beat this and you're strong and you're going to beat this'."*
Family Function	Flexibility	001 – "*We tried to focus my treatments around her life too. We didn't want her life to stop. So, she was still going to school. She was still going to her tutoring. We were still talking about homework. We were still talking about applications, she was in acting, so she still did her theater."* 005 – "*The fact that nothing is going to change in the routine, that they are going to go to school as usual. I think I tried to stick to life and how it's going to change and not change. We as a family tried to do whatever we [could] to make it normal."* 008 – "*We were making sure he would still have a really fun summer and he'd get to do golf lessons and swim lessons and play with his friends so that it wouldn't change his summer, but that my summer might be a little bit different."* 010 – "*They had to step up and sort of become more independent. I said, 'I know you're only 10 to 12, but you know what, you're going to learn how to do their own laundry right now because Mom can't, I'm not going to be there to do everything for you. And you're old enough to do this. You can do this and you're going to start helping with dishes'. They stepped up and they've had to be more independent."*
	Family Cohesion	002 – *"My husband was there, it's like I didn't go through all this alone."* 009 – *"I think we already had a good foundation, and we were a close family, but it definitely brought us even closer."*
	Family Communication	001 – *"I was very open about the fact that I'm not well, [be]cause I was not well, I was very open about the fact that I need to get help and that I was attending classes to help me get help."*

	Open and Honest Communication	002 – "*Our family values have always been honesty. So even if maybe you don't have something that's good news, you still have to probably convey that. But then also say, 'well here's how I'm going to tackle it', or maybe even if you say 'I don't know what I'm going to do'. If they had any questions or concerns, you know I'd always answered them honestly."* 003 – *"We've always been pretty open about everything, especially life and death situations. We never thought about hiding anything from them. I was very open about, about everything."* 010 – *"But I think it probably brought us closer and allowed us to talk more honestly about everything in our lives. There's nothing that's off the table about talking about ever with us."*
Honoring the Self		001 – "*It was always about my kids and what my husband needs, not what I need. So, I had to make a big effort to say, 'I need you to tell me that you like my meal.' And it took some energy from their part to understand why I needed this. I had double D's and they always stuck out. So, when I lost my breasts and I was weak from surgery, I was feeling exactly like a weak, wet bird."* 002 – "*I was in my own little world and maybe not in tune, looking out as to what my children's needs were at the time."* 003 – *"One of the first time that I met with him [oncologist] I asked him, why did I get this? Why didn't somebody else get this, you know, tell me what I did wrong?"* 009 – *"And I told her, 'please don't do that. This is my journey. I respect your friend trying to ease your mind and stuff, but they're not me. And you're taking away from my journey'."*
Emotions	Positive Outlook	002 – "*The prognosis was very good and that I had no worries about my health. I felt very positive and optimistic about my prognosis. So, I myself wasn't really worried and that's pretty much the message that I tried to relate to my sons – that it was very treatable, it was very small, and there was no indication that it had spread anywhere. I wasn't going to be dying anytime soon."* 003 – *"I had a positive outlook on the diagnosis that it would be okay. That was a huge benefit."* 004 – *"It was just an aggravation and a speed bump in my life where it was like, okay, once I have the surgery done, when can I go back to work?'."*
	Previous Experience with Cancer	001 – *"One of the friends of my 16-year-old, they were in school together, well her mom ended up dying from cancer within one month from diagnosis, it was traumatic."* 003 – "*I had an aunt, so we have gone through this process before. My dad's sister had breast cancer. She had a mastectomy, went through the chemo, radiation, all the horrible physical things you go through, and she got better. And then she got re-diagnosed, and she ended up passing some lung cancer. So, I understand her [be]cause I know how it affected my mindset"* 004 – *"Like, okay your grandmother had it. Look at her, there's nothing with her, she is okay, I'm doing this. I'm going to be fine. It's no big deal. It's stage one. It's nothing."* 006 – *"She had a friend whose mother had recently died of breast cancer. So, that made it scarier."*
	Protecting Children	004 – *"You tried to shelter them, but I think they were old enough and I think they need to know*." 006 – *"I remember thinking as I was going through treatments, 'this this horrible, but at least it's not my daughter going through this'."*

	Fear and Guilt	001 – *"I felt so bad that she was 16 and she had to go through the fear of losing her mom."* 009 – *"And it was hard on me because I felt like, like to miss out on so much in high school, because I got sick when he started high school."*
	Worrying about Extended Family	001 – *"I was worried about my parents. I did not want them coming here. I felt that I wanted my time alone to heal and process. And I thought that if she [mom] was here, she could be cooking for us, but I would be worried about her needs."* 003 – *"My mother was in the early stages of Alzheimer's when I was diagnosed, so I chose not to tell her. She would forget things so frequently. I knew every time she would look at me, she would ask me what was wrong with my hair"* 006 – "*My mother was still alive at that time. And I feel sorry that she had to go through that worry with me. [Be]cause I was not afraid to express my emotions. I felt bad and was so worried and all that about dying.'*
Social Circle of Ill Parent	Emotional Support	001 – *"And the people who supported me, I feel much closer to them now, those people, because I can talk to them and not worry because they were with me all along."* 007 – *"We have a pretty wide social circle and caring family and friends, very supportive network."*
	Tangible Support	006 – *"Our community came together for our daughter. My daughter, she had a good, wonderful group of friends whose parents would step up to, and the school stepped up. She was involved in that play I think they gave her part. So, she could be a part of this while her mother was going to go through this."* 010 – *"I have one friend who was really there for me. She came to a couple of chemos with me. She organized meals for my family. She was a good friend before, but she was the one who stepped up and was there for me."*
	Lack of Support	004 – *"My friends were so against and up in arms because everybody just thought that I was going to die, it would have been nice to have had the support of my friends. And I'm sure my family thought I was a like crazy too."* 009 – *"So, it just seemed like people kind of stayed away. And some people don't want to talk about it. Some people, once you start talking about it more, it makes them uncomfortable."* 010 –*"Like my mother tried to say that, well isn't her Parkinson's worse than my cancer? And then she tried to say, 'Oh, are you going to believe in God now because you have cancer?' And I'm like, Oh my God, shut up! My mother and I did not have a good relationship. It just kind of divided us even more, I kind of saw how shitty she was. You just see who's there for you and who isn't."*
Medical Journey	Diagnosis and Treatment Story	001 – "*After you're done with the surgeon, you move to the oncologist. So, the surgeon makes all of the decisions when you're first diagnosed, because he's the one that has to check. So, I went in to be checked by the surgeon, to decide if we are going to do surgery, you know, how and all of that. So, he's the one following up."* 003 – *"You get diagnosed and then they send you to an oncologist and then he tells you what the process is going to be. Then you go to a surgeon and then you get a port within a week."* 004 – *"I can't really tell you because I wasn't paying attention because I knew I wasn't going to do the chemo route. So, it wasn't important to me to know."*

		010 – *"When they brought me back and they said, well, it's cancer. And then I really didn't hear a lot after that because my brain is just like, fuck!"*
	Memory Issues	007 – *"I couldn't remember stuff, the treatment was so intense."* 009 – *"I don't remember exactly because you know, at this point it's been a month of post-surgery and the dreams and you know, all of that. I don't remember exactly how and what he said."*
	Salience of Medical Environment	001 – *"It is a very disturbing place. Really sick people that are people doing chemo, with no hair that are looking really sick, that are with masks. It's a very, very sad place. I try to kind of blocking or like not focus on that. Looking at something else because it can get to you. Now my plastic surgeon on the other hand is a beautiful plastic surgery office. You don't really see that many patients. So, there I felt a little bit more comfortable."* 003 – *"The oncologists were very standoffish, and I hear [that] from other people in this area. They're not very proactive, they're very reactive to treatment"* and when she asked what may have caused the cancer *"his response was 'we'll never know. That's not what we need to focus on, we need to focus on that you will recover, let's focus on the positive, let's focused on the recovery"*
	Mental Health Services	008 – *"It was something that University of [state] put together. Later in my treatment, I met with a psychologist there, that focused on oncology. And my oncologist was awesome about giving referrals. I think that I was really, really anxious about that, so at my first chemo, for example, that they would have connected me with him. ."* 006 – *"My employer had started an EAP program, an employee assistance program. And so, I went to see the, see this person, and I specifically asked somebody, a counselor who had, worked for, worked at hospice. I needed to talk about all my death issues."* *002 – "[The oncologist] pushed support groups, but for me it wasn't something I really wanted to participate in because I just really didn't want to sit with a bunch of people and discuss, like the disease. What I really didn't want was just hurting people who were stage three and stage four, who really had an awful prognosis and that wasn't going to be helpful for me. You know, focusing on the disease."* 009 – *"I had a liaison from the oncologist to help me, but she kind of disappeared. She just, I don't know if they like stopped having liaisons or what, but she just disappeared. I also had a case worker from [insurance company] and she called me a couple of times, but I think that she realized that I had it under control and I had support. So, she kind of disappeared too. I wish she tried a little harder or followed up a little more."*
Post-Treatment Life	Adjustments	001 – "*It changes your relationship with everything, not just people, but it changes your relationship with time. It changes your relationship with your environment. It changes your relationship with your work. So, it changes your life priorities."*
	Getting involved	004 – *"I became a massage therapist. I volunteered at the infusion suite and I would give hand massages to the people that were receiving chemo."* 005 – *"I'm active in a local community organizations, whose mission is to assist those who are going through breast cancer, but also to raise awareness among community members to go beyond just awareness, detection and treatment."*

		006 – *"I joined the national breast cancer coalition, which was a newly formed organization that was trying to end the disease."*
	Identity of Ill Parents	001 – *"I worry a little bit about how other people see me. So at first I was like, 'do they see cancer when they see me? Do they see cancer?'."* 002 – "*It's almost like having cancer is almost like being pregnant, because all of a sudden that's all you become. You know when you are pregnant it's all about the baby and you're like, you're no longer your own person. You're just like, oh baby, baby, baby. Anyway, same thing with the cancer. It was hard because that's what they see, first. And then I know, on one hand you know that people are concerned, and they want to make sure that you're doing okay and all that. But it also got very tiring to always be focused on cancer. Like, I have cancer. It doesn't define who I am."* 004 – *"It didn't become part of my identity as far as I'm concerned."* 007 – *"Cancer is an infection in your body that can be treated. So, keep it on that same mindset. Cancer is not always terminal."*
	Language Centered around Cancer	007 – *"When you hear the word 'cancer', you instantly think of death. When you talk about it, don't talk, talk about [cancer] say that 'this is something you can recover from, like any other illness, don't give any more weight than anything else."* 006 – *"People do say really terrible things to you when you have cancer. They don't mean to say terrible things, but they do because they don't know what to say."* 009 – "*I've always been strong. So, everyone was like, 'Oh, you're strong'. But even strong people have a time in their life where they're not that strong. And people just assume that you're so strong, you're going to get through it."*
Needs of Parents	More Information	002 – *"I don't think I was given any deliberative information on how to talk to your kids."* 003 – "*Everything else I've learned about what I could do to avoid being re-diagnosed with any type of cancer, that unfortunately that didn't come from his [oncologist] office. While you're going through it you have some guidance and after that it's like you're left to figure it out on your own."* 010 – *"I really tried to say, 'no, I want her to come with me' and they were so insistent. So, I don't know what they were afraid of. Would they have talked to me differently? I didn't want them to talk to me differently."*
	Patient Navigators	003 – *"I think it would have been nice if they had that authoritative position. Someone that was talking to them, that have seen other families through it. I think that would have been huge."* 005 – *"I think that needs to be a way for someone to know the rules and responsibilities of everyone in the system. I feel like it would be a fine idea to have like a patient care navigator who can guide not only with issues like cancer, like someone you can ask any questions off, or link you up with other organizations who may have other parents who might have gone through this or like a chat group or something like that. There are some medical facilities that have a nurse navigator or a patient navigator. I think it's called 'patient care navigator', who may be a social worker or mental health provider, or a similar role. But because of my background and my Ph.D., I learned about the different providers, so I kind of knew I had access to them if I needed it. But it makes me, think about those who don't have the same level of access"*

	006 – *"I think it would have been helpful for there to be maybe something for kids whose parents have cancer. I wish there were a lot more services for people with cancer, that was easy to access for people who have life threatening illnesses."* 007 – "*I think that's very important to have a mentor and I really think it's good to have someone that's not family connected. A navigator would have the information on the type of cancer I have. Understand all the other health issues that they're going through and how they are linked together. So, I think a person to know what you may face and to have this person to say to, 'okay, I'm going through this right now, is this normal?' I just think it's more personally to have a person that you can deal with all the time."* 008 – *"I have a master's degree, so I'm going to be higher educated than a lot of patient populations and I'm very inquisitive, so I'll ask a lot of questions, but I do think some places I've heard they have like a nurse navigator or somebody that kind of takes you through the process. But something like that would be helpful. Or even if there was like a family therapist or somebody that they could offer to work with your children."* 009 – *"They could have acknowledged that you have a kid at home. Check in or ask you if you needed any information regarding how to tell, not just your child, but family members as well."*

Figure 1

Level of Interest of Providers for Further Training to Work with Patients and their Families in General

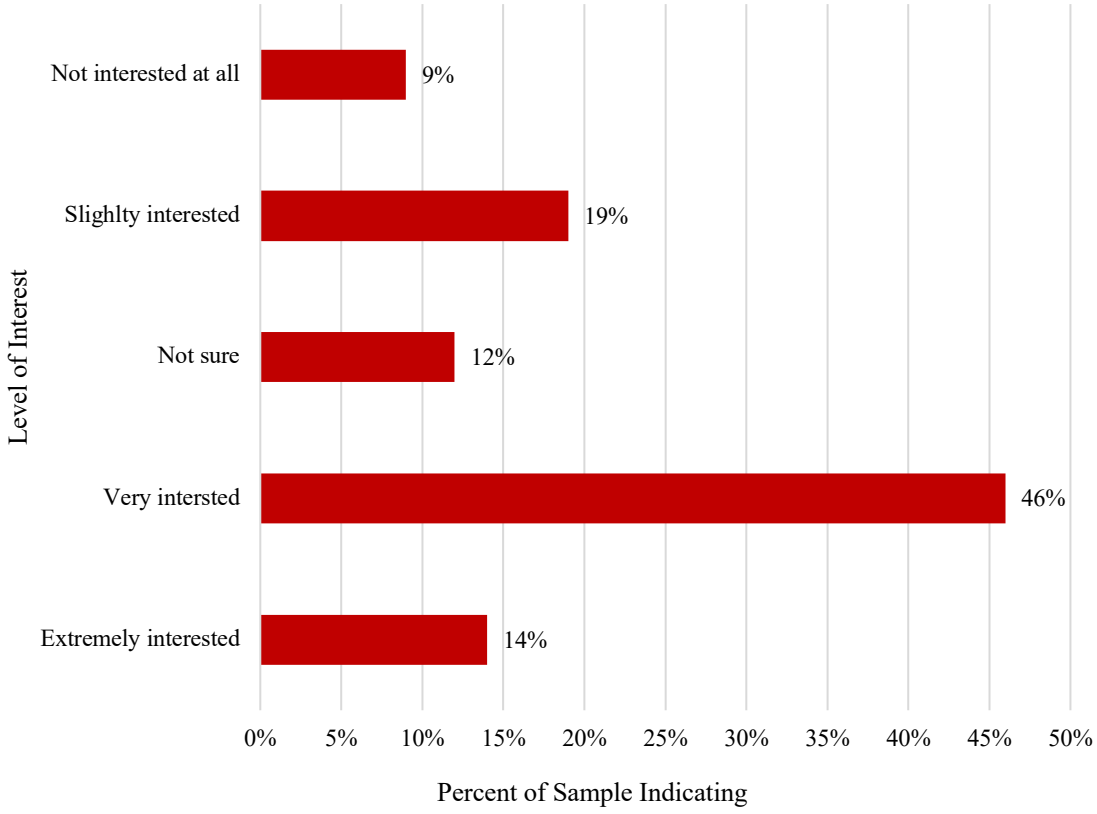
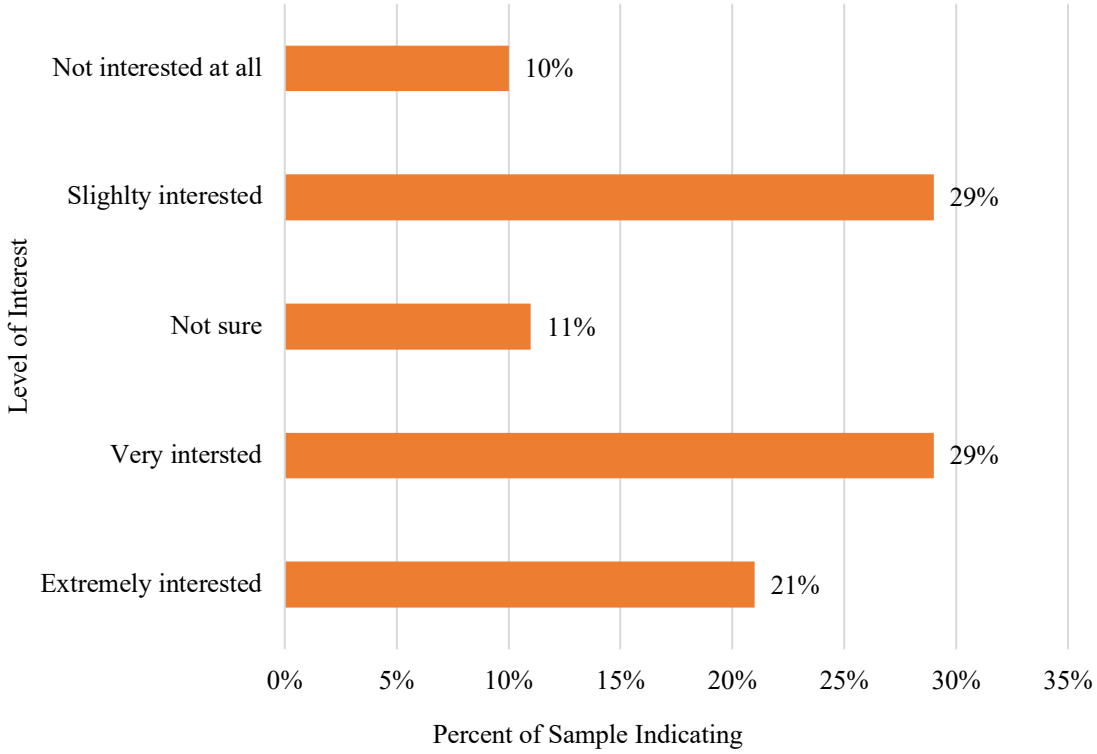


Figure 2

Level of Interest of Providers for Further Training to Work with Parents during their Communication Efforts with their Children



Appendix A

Survey Protocol

1. **What is your gender?** (select all that apply)
    a. Cis (Male)
    b. Cis (Female)
    c. Transgender (Male)
    d. Transgender (Female)
    e. Non-binary
    f. Prefer not to answer
    g. Other____

2. What race do you identify with? (select all that apply)
    a. African American or Black
    b. Asian
    c. Hispanic, Latino, or Spanish origin
    d. Native American, American Indian, or Alaska Native
    e. Native Hawaiian or Other Pacific Islander
    f. White / Caucasian
    g. Prefer not to answer
    h. Unknown
    i. Other____

3. What is your occupation?
    a. Certified Nursing Assistant
    b. Chaplain
    c. Child Life Specialist
    d. Doctor of Osteopathic Medicine
    e. Licensed Practical Nurse
    f. Marriage and Family Therapist
    g. Medical Doctor
    h. Patient Advocate
    i. Patient Care Technician
    j. Psychiatrist
    k. Psychologist
    l. Registered Nurse
    m. Social Worker
    n. Other_____

4. Practice Type (select all that apply)
    a. Private Oncology Practice
    b. Community Hospital
    c. Private Hospital
    d. Teaching Hospital
    e. Academic Health Center
    f. Comprehensive Cancer Center

g. Other____

5. **How long have you been practicing in your field?**
   For physicians (e.g., MD, DO)
   Residency: ____ years
   Post-residency: ____ years
   For non-physician providers (e.g., RN, LMFT, LP, chaplain):
   Internship, practicum, or pre-license: ____ years
   Post-internship or post-license: ____ years

6. **How long have your been practicing in your current position?**
   For physicians (e.g., MD, DO)
   Residency: ____ years
   Post-residency: ____ years
   For non-physician providers (e.g., RN, LMFT, LP, chaplain):
   Internship or pre-license training: ____ years
   Post-internship or post-license training: ____ years

7. How much of your practice involves the care of patients with cancer?
   a. 0%
   b. < 25%
   c. 26 – 50%
   d. 51 – 75%
   e. 76 – 99%
   f. 100%

The next three questions are regarding your training in working with patients' families in general (i.e., considering the entire family – not just the patient).

8. Where did you receive training to work with patients' families? (check all that apply)
   a. In school (e.g., Medical School, Nursing School, Graduate School, etc.)
   b. During residency or post-doctoral training
   c. At professional conferences (e.g., workshops, poster sessions, presentations, etc.)
   d. During my practice (on the job training, supervisor/mentee meetings, collaboration with peers, etc.)
   e. Other: _____
   f. I have not received any training in working with patients' families

*if "e" is selected the survey will go to question #11

9. **To what extent did you receive training in working with patients' families?**
   During my training (e.g., graduate school, medical school) I:
   a. took several semesters of classes, learning how to work together with a patient and their family.
   b. took one semester-long class, learning how to work together with a patient and their family.
   c. took classes in which the topic of learning how to work together with a patient and their family was covered a few times.
   d. had a few hours of training, learning how to work together with a patient and their family.
   e. did not receive training in school.

10. How many workshops have you participated in to learn about systemic care (beyond school)?
   a. I have not taken any workshops since I started practicing.
   b. Between one and two since I started practicing.
   c. Between three and five workshops since I started practicing.
   d. More than five workshops since I started practicing.

Talking to school-aged children (6 -18-year-olds) about a parents' cancer means a lot of different things, from disclosure conversations to ongoing conversations regarding the diagnosis, prognosis, and treatment. The following questions are regarding your training in advising a parent during cancer communication efforts with their school-aged child; both during the initial disclosure conversation and the ongoing conversations regarding the diagnosis, prognosis, and treatment.

11. **Where did you receive training in helping parents during their cancer communication efforts (disclosure - and ongoing conversations) with their school-aged children?**
   a. In school (as part of curricula in Medical School, Nursing School, Graduate School, etc.)
   b. During residency or post-doctoral training
   c. At professional conferences (e.g., workshops, poster sessions, presentations, etc.)
   d. During my practice (on the job training, supervisor/mentee meetings, collaboration with peers, etc.)
   e. Other: _____
   f. I have not received any training in helping parents

if "e" is selected the survey will go to question 16

12. **What type of training in helping parents with cancer communication did you receive?**
   a. Disclosure conversations
   b. Ongoing conversations
   c. Both disclosure and ongoing conversations

d. None

If "a" is selected, only question 13 will be shown, if "b" is selected only question 14 will be shown, if "c" is selected both q 13 and 14 will be shown, if "d" is selected, survey will skip to question 16

13. **To what extent did you receive training in helping parents disclose their diagnosis to their school-aged children?**
    During my training (e.g., graduate school, medical school), I:
    a. took several semesters of classes, learning how to work together with a patient and their family.
    b. took one semester-long class, learning how to work together with a patient and their family.
    c. took classes in which the topic of learning how to work together with a patient and their family was covered a few times.
    d. had a few hours of training, learning how to work together with a patient and their family.
    e. did not receive training in school.

14. **To what extent did you receive training in helping parents continue to talk about cancer, the prognosis, and treatment with their school aged children?**
    During my training (e.g., graduate school, medical school), I:
    a. took several semesters of classes, learning how to work together with a patient and their family.
    b. took one semester-long class, learning how to work together with a patient and their family.
    c. took classes in which the topic of learning how to work together with a patient and their family was covered a few times.
    d. had a few hours of training, learning how to work together with a patient and their family.
    e. did not receive training in school.

15. **How many workshops did you participate in to learn about how to help parents during their efforts in communicating (disclosure - and ongoing conversations) about their cancer diagnosis to their school-aged children (beyond school)?**
    a. I have not taken any workshops since I started practicing.
    b. Between one and two since I started practicing.
    c. Between three and five workshops since I started practicing.
    d. More than five workshops since I started practicing.

The next two questions are regarding your interest in receiving more training in working with patients' families in general and in regard to cancer communication efforts.

16. **What is your level of interest in receiving more training or information about how to work with patients' families generally?**
    a. Extremely interested
    b. Very interested
    c. Not sure
    d. Slightly interested
    e. Not interested at all

17. **What is your level of interest in receiving more training or information about how to help parents with cancer communication efforts (disclosure - and ongoing conversations) with their school aged children?**
    a. Extremely interested
    b. Very interested
    c. Not sure
    d. Slightly interested
    e. Not interested at all

18. **How (a) equipped and (b) knowledgeable do you feel in assisting parents who have cancer in their communication efforts (disclosing the diagnosis and continuing to talk about the cancer) with their children?**

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I feel equipped to:					
talk with parents about how they should tell their children about the diagnosis.					
talk with parents about how they should have ongoing conversations about the diagnosis, prognosis, and treatment.					
I feel knowledgeable about:					
in-person resources related to cancer disclosure communication efforts (e.g., support groups, therapists, etc.) that are available to parents diagnosed with cancer.					
in-person resources related to ongoing communication efforts					

(e.g., support groups, therapists, etc.) that are available to parents diagnosed with cancer.					
hardcopy and/or online resources related to cancer disclosure communication efforts (e.g., informational pamphlets, books, etc.) that are available to parents diagnosed with cancer.					
hardcopy and/or online resources related to ongoing communication efforts (e.g., informational pamphlets, books, etc.) that are available to parents diagnosed with cancer.					

The following question is about your beliefs regarding the interdisciplinary care team helping parents who have been diagnosed with cancer. An "interdisciplinary care team" is defined as anyone who is involved in patients' care, such as medical doctors, nurses, mental health providers, or hospital staff (e.g., chaplain, child life specialist, technicians).

19. To what extent do you agree with the following statements regarding the importance of assisting parents in their cancer communication efforts (disclosure - and ongoing conversations) with their children?

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I believe it is important for the care team to:					
help parents decide how to tell their children **about the cancer diagnosis.**					
help parents **continue to talk** about the cancer, prognosis,					

and treatment with their children					
connect parents to in-person resources about **how to tell** their children about the cancer diagnosis (e.g., support groups, therapists).					
connect parents to in-person resources about **having ongoing conversations** about the cancer (e.g., support groups, therapists).					
provide informational resources to parents diagnosed with cancer regarding **disclosure conversations** (e.g., pamphlets, websites, books).					
provide informational resources to parents diagnosed with cancer regarding **ongoing communication** (e.g., pamphlets, websites, books).					

The following questions are about your beliefs regarding your role, specifically in the interdisciplinary team, how involved are <u>you</u> with helping parents who have been diagnosed with cancer – specifically, in terms of communicating (disclosure - and ongoing conversations) with their school-aged children about the cancer.

20.1 I believe that it is part of my role to help parents decide how to tell their children <u>about the cancer diagnosis</u>.

a. Yes, it is part of my role
b. No, it is not part of my role

**if B is selected, the following options will appear:*

Please select why helping parents decide how to tell their children about the diagnosis is <u>not</u> part your role (check all that apply):

c. It would be beyond my scope of practice and/or skillset
d. It would be unethical for me to do
e. I would not feel comfortable
f. Other: _____

20.2 I believe it is part of my role to help parents continue to talk about the cancer, prognosis, and treatment with their children.

a. Yes, it is part of my role
b. No, it is not part of my role

**if B is selected, the following options will appear:*

Please select why helping parents continue to talk about cancer, prognosis, and treatment is <u>not</u> part of your role (check all that apply):

c. It would be beyond my scope of practice and/or skillset
d. It would be unethical for me to do
e. I would not feel comfortable
f. Other: _____

20.3 I believe it is part of my role to connect parents to in-person resources about <u>how to tell their children about the cancer diagnosis</u> (e.g., support groups, therapists).

a. Yes, it is part of my role
b. No, it is not part of my role

**if B is selected, the following options will appear:*

Please select why connecting parents to in-person resources is <u>not</u> part of your role (check all that apply):

c. It would be beyond my scope of practice and/or skillset
d. It would be unethical for me to do
e. I would not feel comfortable
f. Other:

20.4 I believe it is part of my role to connect parents to in-person resources <u>about having ongoing conversations about the cancer</u> with their children (e.g., support groups, therapists).

a. Yes, it is part of my role
b. No, it is not part of my role

**if B is selected, the following options will appear:*

Please select why connecting parents to in-person resources about having ongoing conversations is <u>not</u> part of your role (check all that apply):

c. It would be beyond my scope of practice and/or skillset
d. It would be unethical for me to do
e. I would not feel comfortable
f. Other:

20.5 I believe it is part of my role to provide informational resources to parents diagnosed with cancer regarding <u>disclosure conversations</u> with their children (e.g., pamphlets, websites, books).

a. Yes, it is part of my role
b. No, it is not part of my role

**if B is selected, the following options will appear:*

Please select why providing informational resources to parents is <u>not</u> part of your role (check all that apply):

c. It would be beyond my scope of practice and/or skillset
d. It would be unethical for me to do
e. I would not feel comfortable
f. Other:

20.6 I believe it is part of my role to provide informational resources to parents diagnosed with cancer regarding <u>ongoing communication about the cancer</u> with their children (e.g., pamphlets, websites, books).

a. Yes, it is part of my role
b. No, it is not part of my role

**if B is selected, the following options will appear:*

Please select why providing informational resources regarding ongoing conversation is <u>not</u> part of your role (check all that apply):

c. It would be beyond my scope of practice and/or skillset
d. It would be unethical for me to do
e. I would not feel comfortable
f. Other:

Appendix B

Recruitment Script

UNIVERSITY OF MINNESOTA

Twin Cities Campus ***Family Social Science*** *290 McNeal Hall*
College of Education *1985 Buford Avenue*
and Human Development *St. Paul, MN 55108*
612-625-1900

Dear Colleague:

My name is Vaida Kazlauskaite; I am currently a doctoral candidate in the Department of Family Social Science at the University of Minnesota. My advisor, and the principal investigator on this inquiry, is Tai Mendenhall, Ph.D., LMFT.

As part of my dissertation study, I am collecting data through a survey that aims to investigate the professional training of medical and mental health providers in supporting parents who (a) have been diagnosed with cancer and (b) have school-aged children. It also explores providers' attitudes toward aiding ill parents in initially disclosing their cancer diagnosis to said children, and then continuing to communicate about their prognosis and treatment over time.

If you are a medical, mental health, or any other professional provider who has worked with cancer patients and are interested in completing the survey, please click on the link below.

The link will take you directly to the survey which begins with the consent from. Once you have reviewed the consent form, you will have the opportunity to opt out if you wish to not participate.

https://umn.qualtrics.com/jfe/form/SV_4YKYAy6lHvmnYwJ

Thank you for your time and considering being part of this study!

Sincerely,
Vaida Kazlauskaite

Appendix C

Recruitment Script

UNIVERSITY OF MINNESOTA

Twin Cities Campus ***Family Social Science*** *290 McNeal Hall*
College of Education *1985 Buford Avenue*
and Human Development *St. Paul, MN 55108*
612-625-1900

You have been identified as a potential participant for a study about parents who have had experience with a cancer diagnosis, and the ways that they communicated about this diagnosis to their school-aged children (6-18 year-old). You have been identified by another parent (who knows you) that I interviewed earlier; this parent told me that you may be willing to take part in this investigation as well.

The study is being conducted by me; I am a doctoral candidate (Vaida Kazlauskaite) from the University of Minnesota in the Department of Family Social Science. I am doing this work as part of my dissertation. I am being supervised in this work by my advisor, Dr. Tai Mendenhall.

If you agree to participate in the study, you will be interviewed regarding your experience with your cancer diagnosis and the way you told your children about it. The interview will last 30-50 minutes. The interview can take place via telephone. You may choose the date and time for the interview.

If you are interested in participating, please contact me via email: kazla007@umn.edu or by telephone (301) 667-0623.

You will be a given a consent form for further information regarding the study, the process of the interview, and details regarding what will happen with the collected interviews. At that point, you can make a decision regarding whether to be interviewed. If you decide to take part in the interview, you are free to change your mind and discontinue your participation at any time.

Thank you for your time and considering being part of this study!

Sincerely,

Vaida Kazlauskaite

Appendix D

Consent Form

UNIVERSITY OF MINNESOTA

Twin Cities Campus ***College of Education and Human Development*** *290 McNeal Hall*
Family Social Science *1985 Buford Avenue*
Saint Paul, MN 55108
612-625-1900

Title of Research Study: Parental Cancer and Communication with Children

Investigator Team Contact Information: Tai Mendenhall, Ph.D., LMFT (advisor)
For questions about research appointments, the research study, research results, or other concerns, call the study team at:

Investigator Name: Tai Mendenhall, Ph.D., LMFT Investigator Departmental Affiliation: Family Social Science Phone Number: 612-624-3138 Email Address: mend0009@umn.edu	Student Investigator Name: Vaida Kazlauskaite, MS, LAMFT Departmental Affiliation: Family Social Science Phone Number: 301-667-0623 Email Address: kazla007@umn.edu

Key Information About this Research Study
What is research?
The goal of research is to learn new things in order to help people in the future. Investigators learn things by following the same plan with a number of participants, so they do not usually make changes to the plan for individual research participants. You, as an individual, may or may not be helped by volunteering for a research study.

Why am I being invited to take part in this research study?
We are asking you to be part in this research because you have been diagnosed with cancer and have had to tell your children about the diagnosis.

What should I know about a research study?
Someone will explain this research study to you. Whether or not you take part is up to you. You can choose not to take part. You can agree to take part and later change your mind. Your decision will not be held against you. You can ask all the questions you want before you decide.

Why is this research being done?
There is a general lack of information and support for parents that have to decide when, how, and how much to tell their children about the parents' cancer diagnosis. The purpose of this study is to understand how parents make these decisions and who can

potentially be helpful during this process. We strive to learn from the parents' experience to understand how medical and mental health providers can work together to aid parents during this process.

How long will the research last?
We expect that you will be in this research study once for the interview. We may contact you with follow up questions or for assistance in making sure that the results represent the participants correctly. The interview will last 45-60 minutes.

What will I need to do to participate?
You will be asked to answer open ended interview questions regarding how you came to the decision to tell your children about your cancer. We will ask you questions regarding how that information was portrayed to your children, who you sought out for help, and who was not available during the time that may have been helpful. More detailed information about the study procedures can be found under "What happens if I say yes, I want to be in this research?"

Is there any way that being in this study could be bad for me?
Although we do not anticipate any harm for this study, there is potential that the interview and the questions asked may bring up some painful memories, which may be uncomfortable for you or cause emotional distress.

Will being in this study help me in any way?
We cannot promise any benefits to you or others from your taking part in this research. However, possible benefits include processing of emotional impact of this experience.

Detailed Information about This Research Study
The following is more detailed information about this study in addition to the information listed above.

How many people will be studied?
We expect a total of 12-15 people in the entire study. The interviews will be conducted with one participant at the time.

What happens if I say "Yes, I want to be in this research"?
If you agree to be in the study, you will be contacted via telephone by the student researcher and an interview time will be set up at a private location; a day and time that is convenient for you will be scheduled. The interview will last about 45-60 minutes. The interview will be conducted in person and will be audio recorded. Once the interview is over, you will be given a resource lists to therapists, in case it is needed after the interview. You may be contacted via e-mail regarding our findings and asked to ensure that we are representing the findings correctly.

What are my responsibilities if I take part in this research?
If you take part in this research, you will be responsible for attending the scheduled interview and answer the posed questions to the best of your ability.

What happens if I say "Yes", but I change my mind later?
You can leave the research study at any time and no one will be upset by your decision. If you change your mind, please contact the investigator to inform them about your decision. Choosing not to be in this study or to stop being in this study will not result in any penalty to you or loss of benefit to which you are entitled. This means that your choice not to be in this study will not negatively affect your relationship with the University of Minnesota.

Will it cost me anything to participate in this research study?
There will be no cost to you for any of the study activities or procedures.

What happens to the information collected for the research?
Efforts will be made to limit the use and disclosure of your personal information, including research study and medical records, to people who have a need to review this information. We cannot promise complete confidentiality. Organizations that may inspect and copy your information include the Institutional Review Board (IRB), the committee that provides ethical and regulatory oversight of research, and other representatives of this institution, including those that have responsibilities for monitoring or ensuring compliance. We may publish the results of this research. However, we will keep your name and other identifying information confidential. If we learn about any of the following, we may be required or permitted by law or policy to report this information to authorities: Current or ongoing child or vulnerable adult abuse or neglect; Communicable, infectious or other diseases required to be reported under Minnesota's Reportable Disease Rule; Certain wounds or conditions required to be reported under other state or federal law; or Excessive use of alcohol or use of controlled substances for non-medical reasons during pregnancy.

Whom do I contact if I have questions, concerns or feedback about my experience?
This research has been reviewed and approved by an IRB within the Human Research Protections Program (HRPP). To share feedback privately with the HRPP about your research experience, call the Research Participants' Advocate Line at 612-625-1650 (toll free: 1-888-224-8636) or go to z.umn.edu/participants. You are encouraged to contact the HRPP if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide input about this research.

Will I have a chance to provide feedback after the study is over?
The HRPP may ask you to complete a survey that asks about your experience as a research participant. You do not have to complete the survey if you do not want to. If you do choose to complete the survey, your responses will be anonymous.

If you are not asked to complete a survey, but you would like to share feedback, please contact the study team or the HRPP. See the "Investigator Contact Information" of this form for study team contact information and "Whom do I contact if I have questions, concerns or feedback about my experience?" of this form for HRPP contact information.

Your signature documents your permission to take part in this research. You will be provided a copy of this signed document.

Signature of Participant	Date
Printed Name of Participant	
Email of Participant	
Signature of Person Obtaining Consent	Date
Printed Name of Person Obtaining Consent	

Appendix E

Interview Protocol

Demographic questions

1. What gender do you identify with?
2. What is your marital status?
3. What is your education level?
4. What race/ethnicity do you identify with?
5. How old are you now/ how old were you when you were diagnosed with cancer?
6. How many children do you have?
7. How old were your children at the time of your diagnosis?

Diagnosis background

1. What type of cancer where you diagnosed with?
2. What treatments have you had?
3. (If in remission) How long have you been in remission?

Communication with children

2. Please think back to the time you decided to tell your children about your cancer diagnosis. What was that experience like for you?
    a. At what point did you talk to your children about your diagnosis?
    b. How did you prepare for this conversation?
    c. How much information did you give your children regarding your diagnosis?
    d. In what ways did you feel like you had the answers to your children's questions regarding the diagnosis?
    e. What type of questions (if any) were you less prepared to answer?

3. In what ways has your family continued to talk about the cancer? (or was it just a one-time conversation?)

4. In what ways have the roles in your family changed during the treatment of your cancer? (*flexibility)*

5. Tell me a bit about your families' emotional bonding during your cancer? (*cohesion)*
    a. What boundaries were set?
    b. In what ways did your family cope with this as a family/separately? (Making joint decisions vs. sole decisions).
    c. Tell me about your relationship with your child(ren).

6. Tell me about your experience with medical/mental health providers and their involvement in facilitating conversations about your diagnosis with your children?
    a. In what ways do you think your doctors could have been more helpful in facilitating such conversation?

b. Did you have a mental health provider during this process? And if so, in what ways were they helpful/or not in assisting your decision about how to tell your children about the diagnosis?

7. Can you think of anyone that was not available, but that would have been helpful during this process?

8. What advice or wisdom would you give to parents who are in similar situations?

Conclusion:

1. Is there anything else you would like to bring up, or talk about that I have not asked you about, that you may think is important to know?

Appendix F

Qualitative Codebook

1. Demographics
    a. Gender
    b. Race
    c. Marital Status
    d. Age now
    e. Age at diagnosis
    f. Number of children
    g. Age of children
    h. Type of Cancer
    i. Education

2. Disclosure – preparing for conversation
    a. With kids
    b. With extended family
        i. Worry
        ii. Stress
        iii. Needing their support

3. Involving Children
    a. Support from children
    b. Parentification
    c. Treatment process

4. Family Functioning
    a. Flexibility
        i. Disruption in routine
        ii. Roles changing
        iii. Re-prioritizing
    b. Cohesion
        i. centripetal - pulling family together
        ii. centrifugal – pushing family apart
    c. Communication
        i. Increased
        ii. Decreased
        iii. Value of communication – open and honest

5. Self-care – honoring the self
    a. Bio (e.g., focusing on physical self)
    b. Psycho (e.g., focusing on mental health)
    c. social (e.g., connecting with friends on purpose)
    d. spiritual (e.g., faith, religion, higher power, belief system)

6. Friends
    a. Receiving emotional support
    b. Receiving tangible support
    c. Not being supportive
    d. Interfering

7. Extended family
    a. Receiving emotional support
    b. Receiving tangible support
    c. Not being supportive
    d. Interfering

8. Ambiguity
    a. Waiting on results

9. Emotions
    a. Needing validation
    b. Feeling guilt
    c. Denial
    d. Vulnerability
    e. Protecting kids
    f. Fear
    g. Agency
    h. Communion
    i. Optimistic

10. Language
    a. Isolating labels

11. Salience of Medical Environment
    a. Negative
    b. Positive

12. Memory
    a. Not remembering
    b. Blocking things out

13. Medical Journey
    a. Diagnosis story
    b. Treatment story
    c. Inclusion of mental health support
    d. Post-treatment life/adjustment
    e. Meaning Making – getting involved

14. Previous experience with cancer
    a. Family members

b. Friends
c. Kids experience it with friends/family/school mates

15. Child doing own research/reading/reaching out for support to understand cancer

16. Communicated Needs
    a. Needing patient navigator/advocate
    b. Needing more information/support from medical/hospital staff

17. Retrospective thoughts on how cancer affected children

99. other

Appendix G

Audit Trail

8/19/20

- Spoke to Tai about the timeline of the dissertation writing, defending, and turning in to committee
- Talked about the options of writing the two papers first and then combining for the committee or writing one big paper and refining it to two papers later for publications

8/24/20

- Met with Jackie B. over zoom to discuss Crabtree and Miller analysis method
- Went through each of the six steps of the method and discussed goals of each step
- Reviewed Jackie's way of organizing the data

10/27/20

- Tai will review interview one and we will go over it during our next meeting (11/3/20)

11/03/2020

- Tai and I reviewed Crabtree and Miller's method in my dissertation proposal and IRB.
- We went through Interview #1 and compared what each highlighted.
- Next steps: Transfer Interview 1 to an excel sheet and make comments about highlighted pieces and whatever else stands out. Also, add memos.

11/10/2020
Meeting Canceled

11/17/2020

- Tai and I reviewed and compared our codes in the excel sheet
    - Vaida was more specific with codes whereas Tai was broader (helps with identifying themes vs. Categories)
- To do for next meeting:
    - start creating a codebook with themes and categories of codes
    - Apply codebook to Interview #1

11/24/2020

- Tai and I went over the very rough draft of the codebook I had and walked through each code, talking about them and explaining them.
- Together, we came up with 11 categories that seemed solid and may have to be consolidated or expanded as we continue coding the following interviews
- For next week, we go through interview 1 again and apply the codebook.

12/1/2020

- Tai and I reviewed the codebook after I added new codes
- Tai to apply codes to interview 001

12/9/2020
Tai and I reviewed our codebook and the codes applied to interview 001. We changed the codes by combining *medical experience* and *journey*. We deleted agency and communion from medical experience and added them to *emotions.* We then went through each sentence of interview 001 and came to a consensus on the codes. We did not have major disagreements, just codes that either I or Tai missed. We discussed the next steps and next several weeks. We will not meet again until 12/29, during this time I will go on to the next interviews and code them with the codebook we made, adding new codes if necessary.

12/29/2020
Tai and I discussed my progress, I completed all ten interviews. It seems that I did not use code 5 as much as we thought I would, as well as code 11. I did however code many things as 99. So, the next I will go through all the 99s and see if I can code them into categories. We have also found a third coder, Jackie B. committed to helping as a third coder and will be looking at random transcripts to see if she agrees with the given codes. She will look at transcripts that Tai does not look at.

1/5/21
Tai and I reviewed the new codebook that included new codes that resulted from the 99 codes. We added 5 new codes, including a subcode to family communication. We spend about an hour discussing the codes and made sure the word choices are validated and I am able to explain them to my committee if necessary. The next steps are for Tai to code 5 interviews and contact Jackie to code 4 interviews.

1/13/21
Tai and I discussed a new meeting time for the Spring (and final) semester.
I will be starting to type of the results, one code a day is the goal. Once we review and hold a consensus meeting, I will edit accordingly.

1/27/21
Tai and I reviewed my progress on both papers. I will continue to seek guidance on the quantitative piece and start typing the results and plug in the statistics as necessary. We talked about the edge of knowledge and my confidence in being the expert on this particular topic. We discussed my concerns about finding things from the interview that have nothing to do with the communication between parents and child. We decided it's good to include them all anyway, to illustrate the findings in a wholesome way. We set a deadline of 2/10/21 to finish pulling the quotes from all the codes and include a narrative.

2/10/21
I have met the deadline of pulling quotes from each code. I struggled a bit to write a narrative for each code and will go back to work on it some more before sending it to Tai

by the weekend. We discussed the next steps of writing the quantitative paper. I will meet with Yiting to get further guidance on analyzing and writing up my results.

2/13/21
I met with Yiting to discuss syntax on correlations. She was very helpful in the set-up of my data. I think I understand more now.

2/17/21
Meeting with Tai: we reviewed Tai's codes on interview 007. We only had one discrepancy in which I missed a code. Tai and I also discussed the introduction section. I will send him the result section this week.

2/18/21
I met with Yiting again to discuss crosstabs and how to interpret them. I am struggling with data analysis.

2/22/21
I met with Jackie B. to discuss timeline of her coding the four interviews assigned to her. We agreed on 3/7/21 as the deadline. She will code individually and we will meet again to review and discuss. We also talked about my struggles with the quantitative piece and how inadequate I feel. She reassured me that I do not need to try and run some complicated analyses to prove myself. She reminded me to stick to the proposal and that my committee already signed off on it and therefore are not expecting anything other than what I said I would do and they signed off on.

2/24/21
Tai and I reviewed interview 003. There were no discrepancies this time, adding rigor to the codebook. The only thing that came up was the emergences of 'anger' in this interview. I will do a word such for anger and its synonyms to see if it comes up in other interviews and if it does, we may add an additional subcode to code number 9 'emotions'. We also discussed my results section, Tai was happy with it saying it was 'a good first draft' which made me happy since I was not satisfied with it in general. Edits on the results section will be made on the weekend and send back to Tai for review.

2/27/21
I send Tai the edited introduction and results section.

3/3/21
Tai and I met and discussed sending the methods and results section to Tim Piehler for feedback. I expressed concern about it not being detailed enough. Tai said he will take a look at it before I send it to Tim.
I received feedback from Tai and send it for review to Tim.

3/9/21
Tim got back to me with the edits. It does not look as bad as I thought it would be. The main feedback was to add more detail to the measure section and add description of the

sub-measures. Additionally, the correlation I ran between provider type and attitude was not appropriate or right. Tim suggested I run a t-test. I spent the afternoon merging the providers into two groups: Medical providers and Mental Health providers and then running the t-test. I think a chi-square (2x2) may actually work better here.

3/10/21
Tai and I met for our weekly meeting and discussed Tim's feedback. I will continue working on it and then write the discussion section. Tai encouraged me to start a new document putting the entire dissertation together. I sent Tai the qualitative discussion section. Today, I am also editing the introduction section that I received from Tai, with his edits and feedback.

3/10/21
I met with Yiting to discuss my output for the t-test and the chi-square.

3/17/21
Meeting with Tai to discuss the writing and agreed on timeline for the next sections of writing. I will be sending him my result sections again for final review of those section.

3/24/21
Meeting with Tai was spent discussing the implications and going beyond stating that curriculum needs to change because that has already been a call of action. We also discussed how we (as researchers) cannot just simply say that we need to add classes to medical, nursing, and graduate curricula, because then students would be in school for 12 years instead of 4. We talked about how cuts have recently been made to make sure programs aren't too long but that it sacrifices important classes and topics. I mention that maybe it is not about cutting or adding but changing. Or making integrating professions, to ensure they work together- work smarter not harder. We agreed that I will send Tai the discussion section for both manuscripts and start on the global abstract and introduction for the dissertation. Four weeks to go.

3/27/21
Reconciliation meeting with Jackie to review the interviews she did.

3/31/21
Met with tai to discuss the discussion sections for both papers. We agreed that I will continue editing the sections as well as work on the global implications, which may help with the discussion pieces. I will send Tai sections to review by this weekend.

4/3/21
Jackie agreed to take a look at my qualitative discussion piece. I sent her the section today.

4/7/21
Meeting with Tai to discuss progress. We spoke intensely about the quantitative discussion section and what it is still missing. We agreed that it should be broken down

into sections for the ease of readers and for organization. I will focus on education, training, and practice to help organize the section. We also agreed that I will send Tai the entire paper by this weekend for review.

4/8/21
Reconciliation meeting with Tai to review Interview 005.

4/8/21
Jackie and I met to discuss the qualitative discussion. Jackie gave some great advice and guidance on how I can strengthen the discussion section.

4/10/21
Draft of the entire document was sent to Tai for initial review.

4/14/21
Tai and I met and discussed his feedback on the draft of the dissertation. His main feedback was making sure the results sections are reviewed, tightened, and ensuring they flow nicely and in order. Additionally, ensuring that all fluff language is omitted and consistency regarding first and third author is there. I will review all his edits and feedback and get it back to Tai by 4/16/21 for another review.

4/19/21
Meeting with Tai to discuss the implication and future direction section. Tai's advice was to focus on the main findings: need for more training – both in school and on job – and highlighting the interdisciplinary team and specific providers that could assist parents, who are in need. Implications need to be referenced by what we already know. So as to show what this study adds to the field. The future directions can be just my ideas about what needs to be done to further understand this topic and how it can be done.

4/21/21
Tai and I met to review the paper one more time, some fine editing was completed. I will go over the entire paper, word by word, line by line to ensure everything flows correctly, there are no grammatical or spelling errors. Final touches on the figures will be conducted as well.

Appendix H

Reflexive Memos

11/30/18
After 001 Interview
The first interview was exciting but tough. I did not anticipate feeling such strong feelings. I had to make sure to stay present with the interviewee and not think about my experience and my situation. I actively had to stop making myself thing about me and focus on the participant.

The participant was great, as anticipated, she spoke in great detail and answered my questions thoroughly. Extending the interview to a good hour.
I think I need to get better with my questions or declare this an unstructured interview, because it is so hard to stay on task. The participant talked about a lot of great questions and I think I did a fair job asking follow ups or coming back to interesting things she said.

I think that I will be able to code/find that open communication and honest communication is the way this participant emphasized. Also, how they think more decisions should be made by the doctors themselves. And they had a person in mind who could/should be the one to help facilitate those conversations.

Note to self: I need to go see a therapist. Or else find a new research topic (lol. Probably the first option is smarter)

T was very sweet and kind, I cannot be more grateful for her wanting to think back to such a traumatic time and willing to share with me

12/1/18
White transcribing 011 interview:

- I spoke too fast during the consent part, but I am happy that I was able to calm down and slow it down a lot!
- I said ‘yeah’ and ‘wow’ way too much!!!
- I think I did a decent job with summarizing what I am hearing from T, several times, but could increase number of this next time.
- Maybe check in with participants more than once

12/14/18
After 002 Interview
This interview felt to go smoother than the first. I was able to stick to my questions more. I felt at times the participant did not feel like she really wanted to be interviewed so they gave short answers at first. But after a while, once they warmed up, they gave more detailed answers. I think I got some great information from them.

Transcribing 002 interview
12/14/18

- I disrupted way less this time! I think it's a sign of feeling more comfortable.
- I kept the 'okay' and 'yeah' to a minimum
- I did not check in with the participant if they wanted to continue
- I need to add gender of children to the interview protocol

04/12/2019
After interview 003
This participant was very detailed about her journey, it was hard to hear about her story but I tried to put away my own experience with it and just listen and use my therapeutic skills of listening and being sympathetic.

She talked about how the conversation about the cancer was continuous and how it helped having the prognosis being positive helped them all cope. Her children's ages were old enough for them to openly talk about and process the information together. Even attending classes together. I know demographically, she is in a different place than previous participants, I wonder if they do it differently in the south.

04/15/2019
After interview 004
This participant had a lot of background of cancer, with her mother, father and sister having it and even having melanoma at a young age. This was so scary for me. I kept thinking, is this the path me and my family are going down? I had to keep telling myself to focus on the interview and not worry about myself for right now. I really should dig into the genetics of both of my parents' cancer and figure out my risk so I can ease my mind. I had a hard time getting a word in with the participant, especially at the beginning. She wanted to tell her story, so I gave her some space.

5/08/2020
After interview 005
First interview after a whole year of working on the questions, the dissertation proposal, and talking about it with various professors and colleagues. The questions seem better than before but still need a little more work. They also need to be edited so that the circumplex model is included.

Participant was very insightful; they were the first ones to mention culture and background influencing the way they experience cancer and even the care they receive. She also mentioned a stigma and access, which is so important when it comes to seeking support.

I loved her idea of drawing out sphere of support, to see who is available to you when you need them. And considering the children's sphere of support and where they get information regarding cancer from others and how you can control it.
They seem to be connected to a lot of other people who have had cancer and will probably be a good resource for more participants.

After transcribing:
I need to learn to be better at asking questions. I tend to drag them out rather than just ask it precisely. Also, I feel weird at times asking for clarification, but need to get better at it in order to truly get the entire story of the participant.

5/15/2020
After interview 006
This participant was so great. She truly took her diagnosis and made basically a career out of it!

I wonder though if her experience with her daughter would have been different if she had a different job (not a school psychologist). (as in how much was it a learned skill/knowing how to talk about difficult conversation because of the educational background versus how much was it a parenting style?)

She had her daughter at the hospital after her mastectomy, which probably influenced the way the daughter processed everything. (still not sure if it is a good or a bad thing having your children witness it in person)

The Circumplex questions make the interview stronger, it really gets into the family dynamics and how cancer affected the relationships, roles, and communication.
To prepare for this interview she did talk to her husband and daughter, so she had some hindsight going into the interview.

Funny how she mentions getting genetically tested, just as I thought about it after the last interview. I had to stop myself from asking her question regarding that process, since that would have been more for me than anything else.

After transcription:
Started being better at being precise at asking questions but then got bad again. While I was doing the interview, I thought it was going really well, but as I was transcribing it I see she spent a lot of time talking about her daughter now (being an adult) and I am unsure this information will be useful. She did talk about guilt and how the gene tests helped ease some of that.

She talked about her mother (different topic, but still interesting) and it points to the fact that parents always worry about their children, regardless of age.
I am unsure what happened, but I do not feel like I followed the questions very well.

05/18/2020
After interview 007
This participant had three kids, and two did not meet the criteria, so I tried to focus on the 17-year-old. This participant was all about self-advocacy and learning how to manage the medical system and speak up when things are not working, which I think is part of being a parent too, advocating to make sure that everything seems right.

I think I did better at this interview and stuck to the questions more than the previous interviews.

After transcription:
This interview seemed very well done but veered off the children topic to more of who can help cancer patients in general.

Some awkward yet beneficial pauses happened. But I think the pauses allowed the participant to think about what they want to say next. Need to work on questions even more to integrate the Circumplex model.

06/24/2020
After interview 008
I was very nervous during this interview, I think it is because this participant was a clinician, like me, and I felt like she was the professional and I am the student, she is more knowledgeable than me. However, at the end she thanked me for the work I am doing, which almost validated me and made me feel like she did not see me as less knowledgeable than her. This participant had two kids one of them which didn't meet criteria, so I just asked her to focus on the 8-year-old, which worked out better than the previous interview. I need to be straight forward with the questions, again not asking 3 questions in one.

After transcribing:
I think this interview was the most straight forward yet. The questions flowed much better and truly integrated the Circumplex model.

I think she is the 4th or so person to mention a patient navigator. This is something to keep in mind when analyzing.

9/11/2020
After Interview 009
I liked the way this interview went. I think I did well with leaving silence be silence and not feel like I have to fill it and therefore gave the participant more time to think and say something. Before, I would be quick to say something to interrupt the silence so that it wasn't awkward, which probably made me miss out on some more information.
I liked the way I asked her to elaborate on some things.

Things I could have done better: at the point where she was talking about the liaison and case worker, I moved on too quick. I think I returned back but it needed a better transition between the question regarding who was there/should have been there to the flexibility question.

She brought up a lot of points regarding her extended family, in particular her siblings. This was kind of new. I wonder if it is because she has siblings/is closer to them than my other participants.

After transcribing:
This interview has made me realize how unique everyone's story truly is and it makes me wonder how I will be able to categorize those experiences together for my results.

10/15/20
After Interview 010
This participant was really open and insightful, she was willing to share her entire experience. Her children were aware and more involved than others, I think. It is interesting that the doctors did not want the child to go back with her mother at the initial diagnosis. I wonder if that was because they wanted to protect her or because of their own discomfort and lack of knowledge how to handle the diagnosis talk with a child present. Either way, if a parent wants their child in the room with them, they should be allowed. Each parent knows their children the best and if someone thinks they can handle such information, they should not be told no.

After transcribing:
I feel like I still struggle with asking one question at a time. I often ask at least 3 at a time which may overwhelm the participant or allow the participant just to answer one and feel like they answered it all. They are probably just answering the first or last question since that is what they focus on/recall. I feel like there were times where I could have asked more to follow up questions to get a clearer picture or get more information.

11/18/2020
I am struggling to write the code book. Word association is not a skill I have and therefore I am having a hard time writing the categorical word for all the codes we have. The motivation is there but I am also having a hard time to just sit down and write and do the work. I am tired and ready to be graduated. May seems so close yet so far away and so much work has to be done before I can even begin to think of defending. Aimee found out the last day to defend is May 17th I must set a date at the end of march and send the final papers to the committee by then. 4 months to go.

1/15/2021
DEFENSE DATE IS SET. I am excited the committee was able to come to an agreement on a date from the first doodle poll I sent. The defense date is May 12th, which means I have to send the finished product by April 21st. A lot of work to do, but I am excited to have a deadline.

1/18/2021
I completed writing the results for code 2. It took me a while to get into the groove but once I got into it, it was fairly easy. I think I wrote a lot, well took a lot of quotes. I think I will need to consolidate by synthesizing the quotes into my own words and use less quotes to show.

1/19/21
As I am writing and using quotes for code 3 I am wondering if it will be important to write about all codes. I think some of the codes have nothing to do with communication

and I am wondering if we should only use the communication codes and leave the others for another paper. This should be discussed with Tai next meeting.

1/20/21
Writing on code 4a – adaptability. Running into the issue of who is adapting. Again, the focus of the paper is communication and children. So, what I did was only include 4a when it came to adapting of the children – or trying to maintain the routine.

1/27/21
Continue to work.write.push. That is the mantra. I need to get my confidence up and acknowledge that I AM the expert on this topic. I think it is important to highlight that these studies have not been done before and that (especially) the quant is an exploratory and descriptive study.

2/2/21
It is getting easier to write. I think it was helpful to just schedule time in my day to focus on just writing without having to shift my attention to any other task. I am more confident now that I will finish in time.

2/12/21
The codebook is now complete, and I think it is a good one. I am asking Jackie to help on the coding process to see if she agrees with my coding. Having her on the project will help me even further, she is such a great researcher and writer.

2/15/21
I got so much done this weekend. Sometimes I surprise even myself when I sit and get a good amount of writing done. It makes me feel more accomplished and confident in myself.

2/27/21
I sent an initial draft of the intro, methods, and results to Tai and I am nervous for the feedback. I struggled with including too many quotes and too little narration regarding each theme and code. I think I will need to go back and make sure I summarize the quotes and give a detailed description of each.

3/1/21
I am not a quantitative researcher. Running the analysis of my data shows that I have no idea what I am doing. I am glad Yiting is there to help and assist in understanding what it is that I am trying to do.

3/4/21
I sent the draft of the methods and results section to Tim and I am hoping for the best. I am very nervous sending it him because I don't want to look dumb. I think it is hard for me to write quantitatively because I have had such little practice. Going back to the notes from Tim's class has been useful and looking at the write ups we had to do for the class has provided me with some language. It makes me worry that I am not more

knowledgeable in quantitative work, because I know I will probably need those skills in my career and saying that I am a qualitative researcher is not going to cut it. I wonder if I should have focused less on becoming a better qualitative researcher and more on understanding statistics.

3/9/21
I was happy to receive Tim's feedback so quickly. Of course, as I suspected it had some things that were completely wrong. However, Tim was nice enough to give me specific feedback on what type of analysis should be run instead and Yiting has agreed to continue to help me.

3/10/21
Met with Yiting. She was extremely helpful in navigating the t-tests and the chi-square. I think I understand now. I am able to articulate what I did and what I found. Which is half the battle.

4/7/21
We are down to two weeks before I have to submit my paper to the committee. I am afraid the paper is not good enough because it lacks organization. I will complete the writing this week and put it all together and focus on the flow of the paper. I hope it will be good enough at the end.

4/10/21
I sent Tai a rough draft of the entire dissertation for review. I think it will need major edits after he reviews it before we can get into the fine editing.

4/16/21
I watched Amy G's defense this morning and her presentation and research was really interesting! She asked rhetorically about what the 'why' is behind her research. I really tried to channel the 'why' today when I edited my global implication and conclusion.

4/18/21
I received Tai's edits on the second draft of the dissertation and now must go through it again. It is still not as clear and concise as we both (Tai and I) want it to be. If I am being honest, I wish I had more time. Time to step away from this and look at it with a fresh set of eyes in a month or two. But this is a luxury I do not have and therefore just need to continue focusing and attempting to make the paper as perfect as it can be.

Changing the way providers work with families is important to me. By changing I mean allowing family members to be present in all forms of communication between doctor and patient. Further, I think it is important to adapt the language they use. Many providers use medical jargon to 'get the conversation over with', not leaving much room for discussion or even questions. Changing language to be more caring and empathic is the goal. To do this, students need to be taught in school and continue training on the job. This also means discomfort for the veteran providers because they will have to not only

learn this new way of talking but also be faced with learning from students/interns/residents/fellows. This can bring up a whole new issue of resistance.

4/20/21
One day until I turn in the dissertation. Up until today I was not confident about the paper, but I think with Tai's edits and feedback, it has gotten much better. I think it is clearer what the implications are and how the study adds to the field. I am getting nervous but excited to share my findings with the committee members.

4/21/21
Today is the day. It feels surreal! As I was talking to Tai about the paper and summarizing some findings, I felt very confident in my work and my findings. I am getting excited to present this to the committee. I am trying to reframe my mindset to 'excited' rather than nervous in hopes that I will be able to calmly present and defend.